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Résumé

L'optimisation des soins de fin de vie dans les unités d'enseignement clinique de médecine à l'aide du questionnaire CANHELP et d'une infirmière facilitatrice : une étude de faisabilité

Christopher Frank, Melissa Touw, Jeannette Suurdt, Xuran Jiang, Phil Wattam, Daren K. Heyland

Cette étude a pour objectif d'effectuer un essai-pilote et d'évaluer l'effet et la faisabilité d'une intervention en amélioration de la qualité dirigée par une infirmière facilitatrice utilisant le questionnaire du projet d'évaluation de la santé au Canada (CANHELP) pour améliorer les soins de fin de vie (FV) dans les unités d'enseignement de la médecine. Sur les 123 patients auxquels on s'est adressé, 67 ont accepté de participer à l'étude et la majorité d'entre eux avait le cancer. Le questionnaire a été rempli par des malades en phase terminale et les soignants membres de leur famille. Les chercheurs ont déterminé les aspects des soins présentant l'écart le plus grand entre la satisfaction et l'importance, et les ont ciblés dans la perspective de l'optimisation des soins de FV. Dans une seconde cohorte, ils ont également procédé au dépistage des symptômes à l'aide de l'Edmonton Symptom Assessment Scale (ESAS). Les chercheurs ont évalué les résultats deux semaines après que les patients des deux cohortes ont obtenu leur congé. La satisfaction moyenne à l'égard des aspects prioritaires s'était améliorée. La satisfaction des soignants s'était aussi grandement améliorée ainsi que les résultats de l'ESAS. Grâce au questionnaire CANHELP, l'infirmière facilitatrice a pu repérer des occasions d'améliorer les soins de FV prodigués aux patients dans les unités de médecine et d'améliorer un peu la satisfaction à l'égard des soins.

Mots clés : fin de vie, dépistage des symptômes, questionnaire CANHELP

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Optimizing End-of-Life Care on Medical Clinical Teaching Units Using the CANHELP Questionnaire and a Nurse Facilitator: A Feasibility Study

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The purpose of this study was to pilot-test and evaluate the impact and feasibility of a nurse facilitator-led quality-improvement intervention using the Canadian Health Evaluation Project (CANHELP) questionnaire to improve end-of-life (EoL) care on medical teaching units. Of 123 patients approached, 67 consented to participate. The majority had cancer. The questionnaire was completed by patients with end-stage diseases and their family caregivers. The researchers identified care issues showing the widest gap between satisfaction and importance and targeted these in order to optimize EoL care. In a second cohort, they also screened for symptoms using the Edmonton Symptom Assessment Scale (ESAS). In both cohorts, they evaluated outcomes 2 weeks post-discharge. The average satisfaction of priority items improved. Also, caregiver satisfaction improved significantly and ESAS scores improved. Using CANHELP, the nurse facilitator was able to identify opportunities for improving EoL care in patients on medical units and for making small improvements in satisfaction with care.

Keywords: end of life, hospital care, nursing role, symptom screening, palliative care, The Canadian Health Care Evaluation Project (CANHELP) Questionnaire

Background

It is often said that every system is perfectly designed to get the results that it gets! Canadian research has had poor satisfaction with end-of-life (EoL) care in the hospital setting, which suggests that the health-care system needs to be changed to better meet the needs of people with advanced chronic illness (Heyland et al., 2005). Change initiatives should be informed by the experiences, unmet needs, hopes, and expectations of patients and their families. However, efforts to improve care, particularly at EoL, are often hampered by inadequate definitions of quality and sub-optimal measurement tools (Brown University Centre for Gerontology and Health Care Research, 2004; Lo, 1995; Mularski et al., 2007).

We recently validated a novel questionnaire to measure the quality of EoL care, the Canadian Health Care Evaluation Project (CANHELP) questionnaire, developed expressly for patients with advanced chronic illness, both cancer and non-cancer (Heyland et al., 2010b). To determine high-priority areas for improvement in this population, we interviewed more than five hundred seriously ill hospitalized elderly patients and their families. We asked them what was important to them in terms of care at EoL and how satisfied they were with the quality of their care. By juxtaposing importance and satisfaction ratings, we developed a prioritized quality-improvement agenda. We chose to focus on those aspects of EoL care that were considered important by respondents but were the least satisfactory to them. Priority areas for improvement that we identified from the overall perspectives of patient groups related to a feeling of peace; assessment and treatment of emotional problems; physician availability; and satisfaction that the physician took a personal interest in them, communicated clearly and consistently, and listened (Heyland et al., 2010a). Similar priorities were identified from the perspectives of family members. Additional family priorities included timely information about the patient's condition and discussions with the doctor regarding final location of care and use of EoL technology. This approach can also be used to identify care priorities in an individual patient.

We developed a nurse role to administer individualized CANHELP questionnaires and to link patient responses to the clinical team. This role was adapted from several existing nursing roles intended to improve care for hospitalized patients. A Canadian qualitative study of nurses' perceptions of barriers to good EoL care on admission to acute-care hospitals found that frontline nurses are "being pulled in many directions" but that an important nursing skill for optimizing care is "creating a haven for safe passage," through advocacy, support, and striving for an optimal care environment (Thompson, McClement, & Daeninck, 2006). The importance of nursing advocacy in EoL care is discussed in the literature (Adams, Bailey, Anderson, & Docherty, 2011; Canadian Nurses Association, 2012; Thacker, 2008).

Nursing plays a key role in EoL care in hospital. The nurse navigator in cancer care helps to guide patients through the health-care system and to optimize care and adherence to treatments. The role has been shown to improve adherence to oncology follow-up, but the impact of this approach on symptom outcomes has been variable (Wells et al., 2008). Oncology inpatients who had been seen by an oncology nurse navigator to guide their course of care and their interactions with health-care providers rated their distress as lower compared with usual care (Swanson & Koch, 2010).

Nurses assume the role of "key worker" in the provision of palliative care. This model uses an expert working with a multidisciplinary team, coordinating physical and psychosocial care, and assisting with transitions across health sectors (Committee on Palliative and End-of-Life Care for Children and Their Families, 2003). A more "traditional" nursing role is that of advance practice nurse working within a consultation model to advise on care concerns.

In addition to using the CANHELP questionnaire, we wanted to explore the role of systematic symptom screening in patients with advanced chronic illness in the acute-care setting and to determine whether this screening augmented the information provided by the CANHELP to the medical team. Systematic symptom screening has been studied in palliative cancer patients and has been shown to increase the identification of significant symptoms compared to patient reports provided during an interview (Homsi et al., 2006). However, patients do not always view systematic screening positively. In one study they found the screening questions intrusive and were unclear about the purpose of the screening (McGrath et al., 2005). The Edmonton Symptom Assessment Scale (ESAS) is a validated tool that has been used to measure symptom burden and distress in patients with cancer and heart failure (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991; Sigurdardottir & Haugen, 2008). To our knowledge, there are no published studies of systematic symptom screening in a population at high risk of dying in hospital on an acute-care general medical unit.

The purpose of this study was to pilot-test and evaluate the impact and feasibility of a nursing-led quality improvement intervention using the CANHELP questionnaire with or without systematic symptom screening, to identify clinical areas for improvement in care for patients with a high risk of death admitted to acute-care medical units.

Methods

The study was a single-centre pilot of a quality-improvement intervention administered on clinical teaching units at the Kingston General Hospital in Kingston, Ontario. There were two sequential cohorts of patients, the first using the CANHELP only and the second using the CANHELP with the ESAS.

Setting

At the time of the project (November 2008–June 2009), the Kingston General Hospital had four internal medicine clinical teaching units (CTUs), each caring for up to 40 patients. The medical staff consisted of attending physician, senior resident in internal medicine, and junior house staff from internal medicine or other disciplines. There was an advance practice nurse affiliated with the CTU patients but there were no nursing roles related to EoL care. The Kingston General is a 438-bed tertiary care teaching hospital. The research nurse (referred to as "nurse facilitator") was not linked formally to any of the CTU teams but saw patients from each team as indicated.

Patient Population

Patients who met the following criteria were eligible for both phases of the study:

(1) 55 years or older

(2) one or more of the following medical diagnoses:
  - *severe chronic obstructive lung disease (COPD)*
  - *severe congestive heart failure*
  - *advanced cirrhosis*
  - *cancer* — metastatic cancer or stage IV lymphoma
  - *end-stage dementia* (inability to perform all ADLs, mutism or minimal verbal output secondary to dementia, bed-bound state prior to acute illness) (For these participants, assessment would be done through the caregiver or the family.)
  - OR *over 80 years of age and frail* — Canadian Study of Health and Aging Clinical Frailty Scale rating of 6 (moderately frail) or 7 (severely frail) (Rockwood et al., 2005)

(3) estimated hospital stay of at least 5 days, to allow time for medical stabilization and for interventions identified on the CANHELP questionnaire

These criteria defined a group of patients with end-stage disease associated with a 50% probability of survival at 6 months based on previous research (The SUPPORT Investigators, 1995). Patients who did not speak English were excluded.

Eligible patients admitted to the Kingston General were identified to the nurse facilitator by the attending physician, medical residents, and other health-care staff. In addition, the nurse reviewed the charts of all new admissions to identify possible participants, particularly after days when patients were admitted to the service through the emergency department.

Participants were asked to identify, if applicable, a family caregiver, defined as the family member/significant other/close friend who "provides the most care to the patient and is not paid to do so." Those individuals identified as family caregivers were approached for recruitment as well.

The Canadian Health Care Evaluation Project (CANHELP) Questionnaire

The details of our initial development of the CANHELP questionnaire have been published elsewhere (Heyland et al., 2006, 2010b). We have demonstrated that the CANHELP questionnaire correlates, as expected, with other established measures at EoL (construct validity), has good internal consistency (Cronbach's alpha > 0.70), and can be grouped into valid subscales (Heyland et al., 2010b). We have developed one version for the patient and two versions for the family caregiver (one if the patient is alive, the other if the patient has died). The patient version contains 37 items in the following subscales: Relationship With Doctors (4 items), Illness Management (14 items), Communication (5 items), Decision-Making (4 items), Role of the Family (6 items), and Your Well-Being (4 items). In the family questionnaires, the factors are Relationship With Doctors (4 items), Characteristics of Doctors and Nurses (5 items), Illness Management (10 items), Communication and Decision-Making (6 items), Your Involvement (7 items), and Your Well-Being (6 items). (The current questionnaire is available at www.thecarenet.ca.)

Intervention

The nurse facilitator was trained in the use of the CANHELP questionnaire and administered it face-to-face with participants or family members. This was done the second day after admission to allow for stabilization of the acute phase of the illness and sufficient time for care issues or concerns to be identifiable by patients or family members.

Two cohorts were sequentially assessed using the CANHELP, the first using the CANHELP alone and the second using the ESAS as well. The Charlson Comorbidity Index and the Palliative Performance Score (PPS) were used to assess the status of all identified patients. The PPS is a validated tool for assessing function and prognosis indirectly in people with cancer (Anderson, Downing, Hill, Casorso, & Lerch, 1996). It has been shown to reflect functional status and to relate also to prognosis of people with a non-cancer diagnosis (Harrold et al., 2005).

We used a computerized algorithm to identify the items with the largest gap between the participant's satisfaction and level of importance. We then provided a hard copy of a report that ordered or ranked the care issues with the largest gaps at the top; we identified these as "improvement opportunities." The nurse facilitator attempted to collaborate with the health-care team by informing them of the top 10 opportunities identified and working on strategies to assess these. Interactions with members of the medical team on the CTU were done via face-to-face contact and through the use of a standardized form to show areas of importance and areas of current satisfaction or dissatisfaction with care and to offer practical suggestions for improving each of the care concerns (see Appendix 1 for a sample of this form). Care issues were raised at multidisciplinary team rounds and identified in chart progress notes. In cases of urgent or severe symptoms, medical house staff were contacted directly. Management of these symptoms followed usual hospital practice. The nurse worked with house staff to identify patients for whom palliative care and/or social work consultation was appropriate based on the unmet needs identified in the CANHELP questionnaire.

First Cohort

The CANHELP questionnaire was administered by the nurse facilitator to a convenience sample of 33 enrolled patients and available family caregivers to assess ratings of importance and current level of satisfaction with different aspects of EoL care.

Second cohort

Based on the same inclusion criteria, a subsequent cohort of 34 patients was identified. In this phase, however, patient symptoms were also assessed using the ESAS, completed by the patient or, if the patient was unable to do so, by the nurse (Bruera et al., 1991). The ESAS scores were used to identify symptom concerns for medical staff and to monitor response to treatment over the course of hospitalization.

Two weeks after discharge home, another CANHELP questionnaire (ratings of satisfaction only) was mailed to patients in both cohorts at their homes. Patients in the second cohort also received a repeat ESAS tool. Participants were telephoned 2 weeks later if there was no response, and the questionnaire was sent a second time if there was no further response. If a caregiver survey was completed and the patient died, the follow-up survey was completed where possible. No interventions were provided based on post-discharge responses.

The Research Ethics Board at Queen's University Health Sciences and the Affiliated Teaching Hospitals Human Research Ethics Board approved the protocol as a quality improvement initiative. Participants received a verbal description of the process but were not required to give written consent.

Analysis

Given the pilot nature of the study, no sample-size calculations were performed and a convenience sample was used. Characteristics of CTU patients and caregivers were described as counts and percentages for categorical variables and as means with standard deviations for continuous variables.

For both cohorts, the main outcome was change in satisfaction with EoL care as measured by the CANHELP satisfaction questionnaire completed during hospitalization compared with after discharge. The satisfaction scores for the 10 improvement opportunities were compared before and after the intervention using paired *t* test.

Secondary outcomes were as follows: number of palliative care consults, referral to social work and home care services, death rates, and discharge destination. In the second cohort, in addition to the above-mentioned outcomes, we examined the change in ESAS scores (total and subsection scores) over the course of hospitalization.

Results

Of the 123 patients approached, 67 (54.5%) were recruited to the two phases of the project (33 for phase 1 and 34 for phase 2). Only 30 caregivers were available to be approached for the project and 13 of these (43.3%) agreed to participate. Figure 1 summarizes the reasons why patients and caregivers did not participate. The most common reason why patients did not wish to be involved was presence of symptoms or feeling overwhelmed by their illness. Demographic information for all study patients is shown in Table 1. The majority of patients (64.2%) had cancer as their primary diagnosis, while 23.9% had moderate to severe COPD. There were no patients with severe dementia as their inclusion diagnosis. The median PPS of patients was 50%.

The top 10 improvement opportunities are shown in Table 2. The most common issues in the top 10 were those related to self-care management, adequacy of home care services, and sense of being a burden on others. There was a statistically significant improvement in the overall mean satisfaction score of items that were ranked in the top 10 improvement opportunities. In the first cohort, the mean score at the initial visit was 3.2+/-0.7 and at follow-up was 3.8+/-1.0 ($p < 0.0001$). In the second group, the mean score at the initial visit was 3.1+/-0.8 and at follow-up was 3.4+/-1.1 ($p = 0.008$). The difference in the change in satisfaction scores between the two interventions was not significant at 0.3 ($p = 0.14$). Caregiver improvement opportunities are shown in Table 3. There was a statistically significant improvement of scores on the improvement opportunities (initial visit 2.8+/-0.9 vs. follow-up visit 3.3+/-1.2; $p < 0.0001$).

Figure 1 ***Patient and Caregiver Flow Diagram (Phases 1 and 2)***

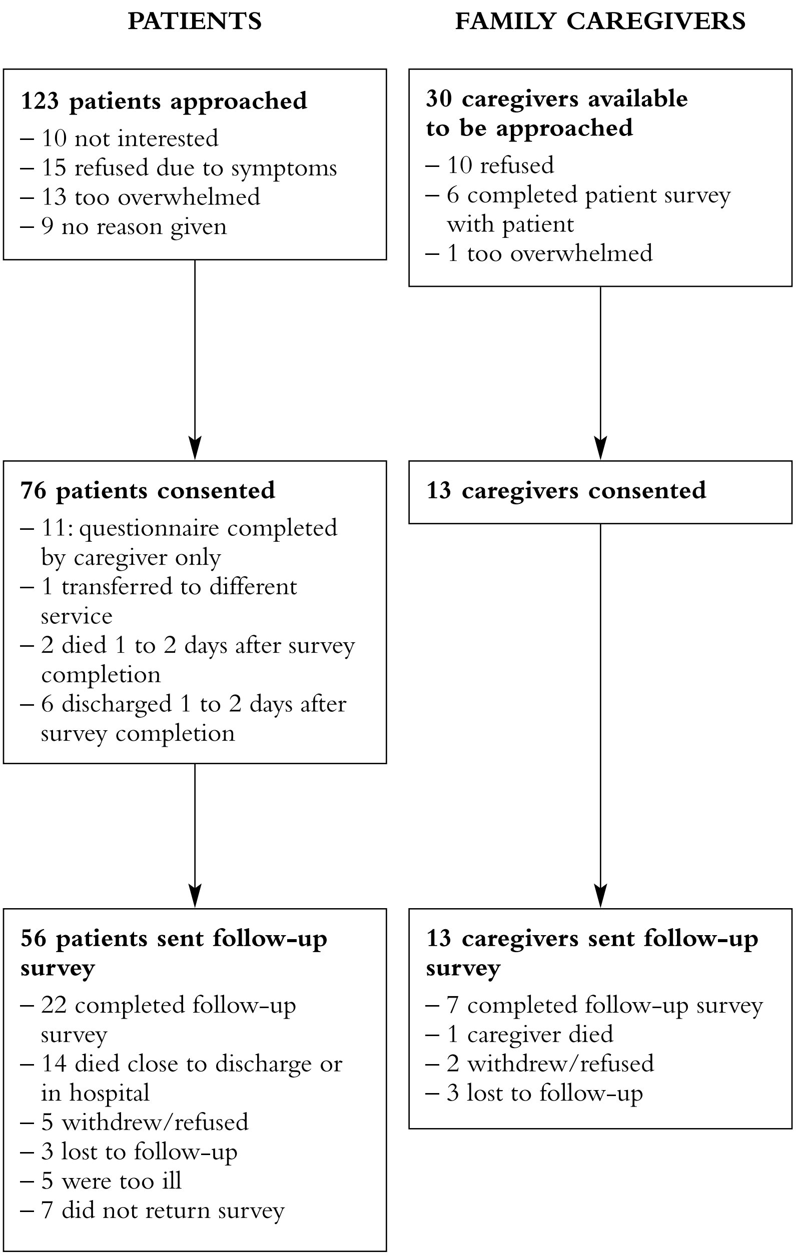

Table 1 ***Patient Characteristics***

	First Cohort $n = 33$ (%)	**Second Cohort $n = 34$ (%)**	***p*** **value**
Gender			
Male	10 (30.3)	12 (35.3)	0.66
Female	23 (69.7)	22 (64.7)	
Age (mean ± *sd*)	76.1 ± 9.6	74.7 ±10.7	0.58
Age 80	8 (24.2)	5 (14.7)	0.32
Charlson Comorbidity Index (mean ± *sd*)	5.7 ± 2.6	5.0 ± 2.6	0.24
COPD	8 (24.2)	8 (23.5)	0.95
Heart failure	3 (9.1)	1 (2.9)	0.29
Cirrhosis	1 (3.0)	0 (0.0)	0.31
Cancer	22 (66.7)	21 (61.8)	0.68
PPS (mean ± *sd*)			0.52
30	3 (9.1)	2 (5.9)	
40	2 (6.1)	6 (17.6)	
50	10 (30.3)	10 (29.4)	
60	12 (36.4)	6 (17.6)	
70	3 (9.1)	5 (14.7)	
80	2 (6.1)	3 (8.8)	
90	1 (3.0)	2 (5.9)	
Marital status			0.40
Never married	2 (6.1)	0 (0.0)	
Married/common-law	14 (42.4)	19 (55.9)	
Separated/divorced	3 (9.1)	2 (5.9)	
Widowed	14 (42.4)	13 (38.2)	
Education			0.21
Elementary school	2 (6.1)	0 (0.0)	
High school	19 (57.6)	15 (44.1)	
College	11 (33.3)	12 (35.3)	
University	1 (3.0)	5 (14.7)	
Postgraduate	0 (0.0)	1 (2.9)	
Other (specify)	0 (0.0)	1 (2.9)	*(cont'd next page)*

Table 1 (cont'd)	**(*n* = 33)**	**(*n* = 34)**	
Race			0.31
African/Black North American	1 (3.0)	0 (0.0)	
Caucasian	32 (97.0)	34 (100.0)	
Current employment status			**0.03**
Employed	2 (6.1)	1 (2.9)	
Unemployed	16 (48.5)	7 (20.6)	
Retired	15 (45.5)	26 (76.5)	
Admitted from			
Home, alone	9 (27.3)	6 (17.6)	0.35
Home, with relative	24 (72.7)	27 (79.4)	0.52
Retirement home	0 (0.0)	1 (2.9)	0.32
Urban area	13 (39.4)	23 (67.6)	**0.02**
Rural area	10 (30.3)	12 (35.3)	0.66
Discharge destination	**(*n* = 31)**	**(*n* = 34)**	
Home, alone	3 (9.6)	5 (14.7)	0.48
Home, with relative	15 (48.3)	19 (55.9)	0.39
Home, with paid supports	1 (3.2)	3 (8.8)	0.32
Nursing home	5 (16.1)	3 (8.8)	0.43
Palliative care unit	2 (6.4)	1 (2.9)	
Hospital mortality	5 (16.1)	6 (17.6)	0.78

Table 2 ***Top 10 "Improvement Opportunities" Identified by Patients***

Question: Over the last 4 weeks . . .	**Frequency**
Satisfaction with the level of confidence in ability to manage illness?	14
Satisfaction with the home care services you received?	12
Satisfaction patient not a burden on family or others?	10
Satisfaction with being able to do special things patient wished to do?	9
Satisfaction with knowledge of the doctors in charge of your care?	8
Satisfaction with help received with personal care?	8
Satisfaction with the level of confidence in the ability of a family member or friend to help you manage patient's illness?	8
Satisfaction with discussions with doctors about where patient would be cared for if a situation worsens?	8
Satisfaction with discussions with doctors about the use of life sustaining technologies?	8
Satisfaction with role in decision-making regarding medical care?	8

Table 3 ***Top 10 "Improvement Opportunities" Identified by Family Caregivers***

Question: Over the last 4 weeks . . .	**Frequency**
Satisfaction with degree of understanding what to expect at the end stage of their relative's illness?	6
Satisfaction with the level of confidence in ability to help relative manage his/her illness?	5
Satisfaction with the environment or the surroundings in which the relative was cared for?	5
Satisfaction with discussions with the doctors about the use of life sustaining technologies?	5
Satisfaction with ability to talk comfortably with relative about his/her illness, dying, and death?	5
Satisfaction with ability to manage the financial costs associated with relative's illness?	4
Satisfaction with updates received about relative's condition, treatments, test results etc. in a timely manner?	4
Satisfaction with discussions with the doctors about where relative would be cared for if he or she were to get worse?	4
Satisfaction that the doctors were available when caregiver or patient needed them?	3
Satisfaction with the level of trust and confidence in the nurses who looked after relative?	3

Overall, 32.8% of participants were seen by palliative care, 55.2% were referred to social work during their hospital stay, and 41.8% had a home care consultation prior to discharge. Compared to patients in the second cohort, patients in the first cohort were more likely to be referred to social work (69.7% vs. 41.2%; $p = 0.02$) and there was a trend towards increased referral rates to palliative care (42.4% vs. 23.5%; $p = 0.10$) and to home care services (51.5% vs. 32.4%; $p = 0.11$).

Scores on the ESAS during phase 2 are shown in Table 4. There was improvement in all scores, although nausea and drowsiness did not reach statistical significance.

Nurse facilitator interventions were not formally tabulated but a sample of recommendations made to medical staff arising from patient perspectives on improvement opportunities is shown in Appendix 1.

Table 4 ***ESEA Scores (1–10)***

	Initial (n = 29)	**Discharge (n = 29)**	***p* value**
Pain	2.5 ± 3.2	1.2 ± 1.6	**0.001**
Nausea	0.6 ± 1.4	0.1 ± 0.4	0.06
Depression	2.0 ± 2.8	1.6 ± 2.3	**0.02**
Anxiety	2.8 ± 3.5	1.4 ± 2.0	**0.02**
Drowsiness	2.3 ± 2.3	2.1 ± 2.4	0.75
Appetite	4.0 ± 3.3	2.0 ± 2.3	**< 0.0001**[a]
Feeling of well-being	5.6 ± 2.5	3.9 ± 2.2	**< 0.0001**[a]
Tiredness	4.9 ± 2.6	3.0 ± 1.9	**0.001**
Sob	3.6 ± 2.8	1.9 ± 1.8	**< 0.0001**

[a] Lower score implies improvement of symptom.

Discussion

The CANHELP questionnaire has been developed and used in studies to assess patient and family perspectives on EoL care issues but has never been used as a screening tool to identify care issues for individual patients at high short-term risk of death. To identify such care issues, we asked patients and family caregivers to rate both the importance of and satisfaction with various EoL aspects of care. In this pilot study, we assessed the feasibility and impact of having a nurse facilitator use the CANHELP tool, in conjunction with a screening symptom assessment tool, on process measures and satisfaction with care.

We encountered challenges in enlisting the participation of eligible patients and their families. The large proportion of potential participants who refused to take part (47/123) highlights the difficulty in doing research with a sick, vulnerable population. Enrolment might have been more successful if the approach had been better integrated into the "usual" care processes rather than part of a formal, time-limited project entailing an informal consent process. It should be noted that patients who declined to participate due to being overwhelmed or due to uncontrolled symptoms had a high likelihood of benefiting from the approach. Thus our study may underestimate potential benefits from the intervention in a real-life setting.

For those patients and families who did participate, we observed small but statistically significant improvements in ratings of satisfaction with high-priority aspects of EoL care. In addition, we observed an overall improvement in ESAS scores; however, overall satisfaction did not improve with the addition of systematic symptom assessment. These improvements in ESAS scores in the second cohort were not associated with an increase in rates of referral to palliative care. Formal screening of symptoms in palliative care populations (rather than in general medicine patients) has been shown to be beneficial in identifying symptom issues. However, improvement of patient satisfaction and other positive outcomes arising from the identification of symptoms has not consistently been shown to improve outcomes (Homsi et al., 2006).

A limitation to this study was the uncontrolled design. The feasibility of the intervention was unclear and a primary purpose of the study was to assess this. Studies will now be able to examine the efficacy of the intervention using a superior study design.

The improvement opportunities that were identified represent care issues in which there is a gap between importance and satisfaction. Many of these opportunities may not have been identified in the course of routine care and their identification in the CANHELP likely contributed to the high rate of palliative care and social work referrals in the study. Several of the most common opportunities related to communication and EoL decision-making have been identified in previous studies using the CANHELP (Heyland et al., 2010b). Subsequent discussions with the nurse or facilitated by the nurse appeared to have an effect on satisfaction in these domains.

Although statistically significant changes were observed in satisfaction scores, the magnitude of the effect was low. While it was not formally measured, this effect may reflect inconsistent follow-up by medical staff on recommendations made by the nurse, despite good documentation of care issues and provision of a list of management options. The nurse found that members of the medical team followed suggestions to varying degrees. Frequent change of residents on the medical team (monthly) resulted in difficulties maintaining team awareness of the nurse's role and consistency in following the nursing recommendations. The challenge of advocating for EoL care issues found in this project reflects reports in the literature on nurses' perceptions and experiences of barriers to optimal EoL care on inpatient units (Thompson et al., 2006). These factors could possibly be reduced if the professional administering the intervention was a fully integrated and consistent member of the medical team. Studies with nurse navigators in oncology have shown the benefits of a similar role, but the nurses in these studies had the ability to implement many of the clinical interventions without having to rely on medical staff (Wells et al., 2008). Given the time needed to perform the role played by the nurse in our project, assigning it to medical house staff would not be feasible in most settings.

Despite the positive signals arising from this study on the use of the CANHELP questionnaire, there are limitations to its use in clinical practice. The average time that the nurse took to administer the tool was 20 to 30 minutes, which proved to be a challenge for patients who were medically unwell. This negative factor is countered by the therapeutic benefit of discussing the identified issues with a skilled nurse. Nurses working in a focused role or working in a broad role to improve overall care could use the CANHELP on a general medicine unit to link with the medical team to target satisfaction with EoL care.

Other limitations include the small number of patient and caregiver participants, which limited evaluation of the intervention's impact.

Although previous research has found that patient satisfaction related to hospital EoL care remains relatively stable after discharge, it is uncertain whether the observed changes in satisfaction were attributable to the nurse-led improvement intervention or to changes in location of care (from hospital to home) in this study (Heyland et al., 2009). As noted, there was no control group and the improvement in CANHELP and ESAS scores could relate to positive outcomes of "usual" care regardless of nurse facilitator interventions. As most of the care gaps identified by the CANHELP were not specific symptoms, the use of a concurrent symptom-assessment approach could serve to improve management. However, the impact cannot really be judged from this study.

Future research arising from this project should focus on the use of the CANHELP in ways that enhance the feasibility and impact of the intervention. A shorter version of the instrument is being developed. Perhaps integrating the measurement and implementation strategy into the role of existing team members, as a part of routine care (rather than having it administered by an external research nurse), will improve compliance and effect.

Conclusions

Using the CANHELP to guide management, the nurse role was relevant in identifying improvement opportunities in EoL care among internal medicine patients, improving symptom ratings, and making small improvements in satisfaction with care. Feasibility was limited by the recruitment process and by limited uptake of the nurse facilitator's recommendations by medical staff. Further work is necessary in other settings to further establish the feasibility and clinical usefulness of the CANHELP as a quality-improvement tool.

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Appendix 1 ***CTU Support Services Project***

Improvement Opportunities (Patient Perspective): Sample Recommendation Sheet

Issue	**Importance**	**Satisfaction**	**Considerations**
Your doctor takes a personal interest in you and your medical problems.	5	2	• Consider holding a family meeting at patient's request • Consider being in contact with family physician during admission (shows that physician is up to date about current medical and personal status)
The doctors explain things relating to your illness in a way you can *understand*.	5	2	• Consider patient's education level • Consider a translator, if applicable • Consider patient's learning needs
You have trust and confidence in the doctors responsible for your care.	5	3	• Encourage honest discussions with the patient and family about prognosis, code status, and EOL care • Enhance rapport with the patient • Identify barriers to increased trust and confidence
You have trust and confidence in the nurses responsible for your care	5	3	• Encourage honest discussions with the patient • Enhance continuity of care • Enhance rapport with the patient • Identify barriers to increased trust and confidence
You feel confident in *your own ability* to manage your illness at home.	5	3	• Consult Community Care Access Centre (CCAC) to arrange for home care on discharge • Consider services to manage medications at home • Consult Occupational Therapy • Patient teaching re: management of illness – Pharmacy to educate about medications – Available services when patient is discharged – Long term care accommodations • Consider home supports available (i.e., family or friends) • Consider Long Term Care (i.e., nursing home, retirement home)

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Appendix 1 (cont'd)

Issue	**Importance**	**Satisfaction**	**Considerations**
You discuss options with your doctor(s) about where you would be cared for (in hospital, at home, or elsewhere) if you were to get worse.	5	3	• Consult palliative care • Encourage patient and family/caregiver conversation about expectations at end of life • Assist patient to make a personal plan of care for end stages of life • Discuss end of life care locations with patient (i.e. home, hospital, hospice etc.)
You are not a burden on your family or others you care about.	5	3	• Consult CCAC for home care services • Consider local hospice services • Encourage independence • Arrange for respite care
You are able to manage the financial costs associated with your illness.	5	3	• Consult social work • Consult CCAC
There are services available to look after your health care needs at home.	5	3	• Consult CCAC (Home Care Program) • Consider patient's accessibility to health care services • Consider private services, if patient can afford cost (service list available through Social work and CCAC) • Consider Seniors Managing Independent Living Easily (SMILE) program for community support services (www.von.ca)
The doctors and nurses looking after you are compassionate and supportive.	5	3	• Consider palliative care volunteer program • Consider HELP (Hospital Elder Life) program • Consult social work • Consult palliative care • Consult spiritual care (if applicable to patient)