Mind the gap: Opportunities for improving end-of-life care for patients with advanced heart failure

Patricia H Strachan RN PhD¹, Heather Ross MD², Graeme M Rocker MHSc DM FRCP FRCPC³,
Peter M Dodek MD MHSc FRCPC⁴, Daren K Heyland MD MSc FRCPC⁵; for the Canadian Researchers at the End of
Life Network (CARENET)

PH Strachan, H Ross, GM Rocker, PM Dodek, DK Heyland; for the Canadian Researchers at the End of Life Network (CARENET). Mind the gap: Opportunities for improving end-of-life care for patients with advanced heart failure. *Can J Cardiol* 2009;25(11): 635-640.

BACKGROUND: Patients with advanced heart failure (HF) experience progressive symptoms, decreased quality of life, and more frequent hospitalizations as they approach the end of life (EOL). Understanding patient perspectives and preferences regarding EOL issues is necessary to identify key opportunities for improving care.

OBJECTIVE: To identify, from the patient's perspective, the major opportunities for improving EOL care for patients hospitalized because of advanced HF.

METHODS: A cross-sectional survey of patient perspectives regarding EOL care was administered via interview of 106 hospitalized patients who had advanced HF in five tertiary care centres across Canada. The study compared which aspects of EOL care patients rated as 'extremely important' and their level of satisfaction with these aspects of EOL care to identify key opportunities for improvement of care.

RESULTS: The greatest opportunities for improvement in EOL care were reducing the emotional and physical burden on family, having an adequate plan of care following discharge, effective symptom relief and opportunities for honest communication. The three most important issues ranked by patients were avoidance of life support if there was no hope for a meaningful recovery, communication of information by the doctor and avoidance of burden for the family.

CONCLUSIONS: Advanced care planning that seamlessly bridges hospital and home must be standard care for patients who have advanced HF. Components must include coordination of care, caregiver support, comprehensive symptom management, and effective communication regarding HF and EOL issues.

Key Words: *Advanced care planning; End-of-life care; Heart failure*

Heart failure (HF) is a complex and progressive condition associated with high morbidity and mortality rates, and considerable health resource use (1,2). Approximately 500,000 Canadians are living with HF and 50,000 new cases are diagnosed annually (3). Based on increases in the numbers of the aging population and improvements in the treatment of myocardial infarction, it is projected that the incidence of HF will double by 2025 (2). A recent analysis of 9943 patients in Ontario who were followed after an index hospitalization for HF identified a median survival rate of 2.4 years (4). Of these, patients who had a left ventricular ejection fraction of less than 30% had a one-year mortality rate of 33.3% and a five-year mortality rate of 65.8%. The high morbidity and mortality rates in patients who have HF clearly indicate that care of this patient population must be based

Attention aux écarts : Les possibilités d'améliorer les soins de fin de vie des patients atteints d'insuffisance cardiaque avancée

HISTORIQUE : Les patients atteints d'insuffisance cardiaque (IC) avancée vivent des symptômes progressifs, une diminution de la qualité de vie et des hospitalisations plus fréquentes à mesure qu'ils approchent de la fin de vie (FDV). Il est nécessaire de comprendre les points de vue et les préférences des patients à l'égard de la FDV pour déterminer les principales possibilités d'améliorer les soins.

OBJECTIF : Déterminer, du point de vue du patient, les principales possibilités d'améliorer les soins de FDV des patients hospitalisés à cause d'une IC avancée.

MÉTHODOLOGIE : Cent six patients atteints d'IC cardiaque avancée, hospitalisés dans cinq centres canadiens de soins tertiaires, ont participé à une enquête transversale sur les points de vue des patients à l'égard des soins de FDV. L'étude a permis de comparer les aspects des soins de FDV que les patients évaluaient comme « d'une extrême importance » et leur taux de satisfaction à cet égard afin de déterminer les principales possibilités d'améliorer les soins.

RÉSULTATS : Les principales possibilités d'améliorer les soins de FDV touchaient la réduction du fardeau affectif et physique de la famille, l'établissement d'un plan de soins pertinent après le congé, un soulagement efficace des symptômes et la présence d'occasions de communications honnêtes. Les trois principaux enjeux classés par les patients consistaient à éviter de maintenir les fonctions vitales en l'absence d'espoir de rétablissement suffisant, à s'assurer que le médecin communique l'information et à éviter le fardeau pour la famille.

CONCLUSIONS : Une planification préalable des soins qui assure un lien harmonieux entre l'hôpital et le domicile doit faire partie des soins standard aux patients atteints d'IC avancée. Cette planification doit comprendre la coordination des soins, le soutien des aidants, la prise en charge complète des symptômes et des communications efficaces au sujet de l'IF et des enjeux de FDV.

on knowledge of what patients perceive as important issues related to end-of-life (EOL) care.

Patients with HF tend to have a fluctuating trajectory of illness that has promoted a focus on acute care and optimization of treatment up to the time of death; this focus creates challenges for EOL planning and care (5,6). Specifically, this illness trajectory has contributed to uncertainty about predicting EOL in patients who have advanced HF (7,8) and the tendency to avoid discussions regarding EOL issues (9). Worsening symptoms, progressive decreases in functional capacity (1,10), an increasing frequency of hospitalizations, lower quality of life and increased reliance on informal caregivers (6) are common in patients who have advanced HF. Additionally, they may be offered invasive procedures such as implanted cardiac defibrillators and

¹McMaster University, School of Nursing, Hamilton; ²Department of Medicine, University Health Network, University of Toronto, Toronto, Ontario;

³Department of Medicine, Queen Elizabeth II Health Sciences Centre, Dalhousie University, Halifax, Nova Scotia; ⁴Department of Medicine and Centre for Health Evaluation and Outcome Sciences, St Paul's Hospital and University of British Columbia, British Columbia; ⁵Department of Medicine, Kingston General Hospital, Queen's University, Kingston, Ontario

Correspondence: Dr Patricia H Strachan, McMaster University, 1200 Main Street West, Hamilton, Ontario L8N 3Z5. Telephone 905-525-9140 ext 26157, fax 905-570-0667, e-mail strachan@mcmaster.ca

Received for publication April 14, 2008. Accepted November 17, 2008

pacemakers, which may further complicate the planning and provision of EOL care (4).

Recently, Canadian and international groups advocated for EOL planning and care for patients who have advanced HF (4,11). Outpatients with advanced HF attending a heart function clinic have said that they would prefer to have opportunities to discuss prognostic possibilities in a supportive, hopeful and open way when they feel well enough to process and participate in activities related to planning for EOL (9). While it is essential that the planning and provision of EOL care for patients who have advanced HF is informed by their perspectives and needs, little is known about these needs from patients who are hospitalized because of advanced HF and for whom EOL planning and care is directly relevant.

We previously reported (12) the most important elements of EOL care identified by 434 patients who were hospitalized because of a life-threatening cancer or noncancer illness, as well as the views of 160 corresponding family members. Given the need to develop EOL care that is responsive to the needs of patients who have advanced HF, we analyzed the responses of this subgroup regarding their perspectives on quality EOL care and the key opportunities for improvement of care. A priori, we hypothesized that there would be considerable opportunities for improvements in EOL communication and decision making, and included a specific set of questions pertaining to cardiopulmonary resuscitation (CPR) – the most common EOL decision for this patient population – to enrich our insights into potential areas of improvement in EOL decision making.

METHODS

The study methodology and overall study results have been published (12,13) and, therefore, will be reported in brief. A questionnaire was developed and tested to elicit the level of importance and satisfaction with elements of EOL care (13). The questionnaire included 28 items in the following five domains: medical and nursing care; communication and decision making; social relationships and support; meaningful existence; and advanced care planning. The degree of importance of each item regarding EOL care was assessed using a five-point ordinal scale (1 = not at all important; 2 = somewhat important; 3 = important; 4 = very important; and 5 = extremely important). The degree of satisfaction with aspects of EOL care was similarly assessed (1 = not at all satisfied; 2 = not very satisfied; 3 = somewhat satisfied; 4 = very satisfied; and 5 = completely satisfied).

After approval was obtained from research ethics boards at each institution, a cross-sectional survey was conducted at five tertiary teaching hospitals across Canada. Inclusion criteria for this subgroup were age older than 55 years; hospitalized because of a primary diagnosis of HF with New York Heart Association class IV symptoms or left ventricular ejection fraction of less than 25%; minimum expected hospital stay of 72 h; and able to understand English and provide written informed consent. Potential participants were screened by a research assistant at each site. The following data were collected from the medical records of participants: comorbid diseases, documented EOL discussion and resuscitation order, and palliative and home care consultations. The questionnaire was administered in a face-to-face interview in four sections. Demographic data, functional status as measured by the Katz score (14) and a global self-assessed quality-of-life score were collected. Patients were asked to indicate their understanding about their health status, preferences for prognostic information, level of care and location of death, obstacles to dying at home, relevance of EOL issues to their care, emergency planning, knowledge of CPR, informational needs related to CPR, and roles they would want to have when making decisions about CPR. Patients, family members or in some cases, primary care physicians were contacted by telephone to determine the patient's mortality status at six months.

Analyses

Means ($\pm$ SDs) and proportions (percentages) were used to describe baseline demographics and respondent answers. An 'opportunity

index' (OI) (Table 1) was created to reflect the quantifiable gap between patient ratings of item importance and satisfaction for the same item. This index was derived by identifying the number of respondents who rated an EOL item as 'extremely important' and answered less than 'completely satisfied', divided by the total number of respondents (13). These OIs were listed in descending order, from the largest to the smallest. The OI was intended to assist health professionals with focusing their efforts on EOL issues that were important to patients and had the largest opportunity for improvement.

RESULTS

Patients in the present study were mostly men (65.1%), with a mean ($\pm$ SD) age of 75.8 ± 9.0 years. Patients were predominantly Caucasian (92.5%) and urban dwellers (84%) (Table 2). Katz scores indicated that patients rated themselves as highly independent (5.3 ± 1.3) two weeks before the current hospitalization. Despite this finding, more than 50% of patients rated their overall quality of life as fair to poor during that same time period. Nearly one-half (47.2%) of the patients surveyed did not survive to the six-month follow-up point. Three patients (2.8% of the sample) were lost to follow-up.

The three items rated as 'extremely important' most often by the patients were avoidance of life support if there was no hope for a meaningful recovery, that information be communicated by the doctor honestly and to not to be a burden on their family. The items rated as 'extremely important' least often by the patients were to have the same nurses looking after them, to have spiritual and religious needs met, and to die in the location of their choice. Overall, all patients reported dissatisfaction with at least one element of care. With respect to individual elements, satisfaction with care ranged from 14.4% of respondents saying they were 'completely satisfied' that they had the same nurses looking after them, to 36.7% of patients 'completely satisfied' that they had opportunities to strengthen or maintain relationships with significant others (Table 1).

The OI reflected that from the patients' perspectives, the greatest opportunities to improve EOL care related to reduction of the emotional and physical burden of illness on family, provision of an adequate plan of care and health services availability after discharge home, honest communication about HF from their doctor, relief of symptoms, physicians being available to discuss HF and answer questions in an understandable way, and knowing which doctor is the main doctor in charge of their care. All elements of the OI are displayed in Table 1.

There was a tendency for patients to prefer less aggressive care than they perceived they were currently receiving (Table 3). More patients (44.3%) preferred a home versus hospital death, although one-quarter of the sample had no preference about the location of their death. Many patients (58.5%) anticipated that the burden on their family caregiver and a lack of health care services (48.1%) would be obstacles to a home death. One-fifth of patients surveyed said they had no caregiver who could provide support if they chose a home death. Less than one-half (43.4%) had a plan of care in place that could guide their caregiver should they experience medical problems such as breathing difficulties or became unconscious during their final days of life. The majority (74.5%) said they (or their caregiver) would call 911 and go to the hospital if they experienced such an event. Only 7.5% of patients surveyed said they would call their family doctor or palliative care physician in such circumstances. Very few patients (11.3%) had had a discussion with a doctor about life expectancy. More than one-half (57.5%) of patients understood that they were currently facing or had faced EOL issues. Although all patients in this sample were hospitalized because of potentially life-threatening HF, a number of patients (20.8%) did not regard EOL issues as relevant to them.

Patients differed in their knowledge and perspectives regarding CPR (Table 4). Approximately one-fifth of those interviewed (22.6%) reported they had undergone CPR in the past. Very few patients (1.9%) could identify all four of the possible interventions that could be performed on people during CPR (artificial breathing, chest compressions, defibrillation and drugs), while over one-quarter (30.2%) could not

TABLE 1
Patient ratings of importance and satisfaction of various elements of end-of-life care

Element	Extremely important		Completely satisfied		OI*
	n	%	n	%	
To not be a physical or emotional burden on your family	40	43.5	20	22.0	33
To have an adequate plan of care and health services available to look after you at home upon hospital discharge	39	38.6	16	18.0	30
That information about your disease be communicated to you by your doctor in an honest manner	53	51.5	30	29.7	26
To have relief of symptoms (ie, pain, shortness of breath, nausea, etc)	36	34.0	21	19.8	25
That your doctor is available to discuss your illness and answer questions in a way that you understand	34	33.0	18	17.6	21
To know which doctor is the main doctor in charge of your care	33	31.4	29	28.2	21
To receive adequate information about your disease, including the risks and benefits of treatment options	27	26.0	23	22.1	19
To have trust and confidence in the doctors looking after you	41	39.0	36	34.3	18
To have someone listen to you and be with you when you are feeling sad, frightened, anxious or confused	28	27.2	21	22.6	17
To have an opportunity to discuss your fears of dying	14	14.9	15	23.8	16
To have information regarding your medical history and needs be readily available to doctors treating you on admission to hospital	35	33.7	26	25.7	16
To have trust and confidence in the nurses looking after you	23	21.9	23	21.9	15
To be involved in decisions regarding the treatments and care that you receive	25	24.3	20	19.6	15
To be treated in a manner that preserves your sense of dignity	29	27.6	27	25.7	13
To receive help with making difficult treatment decisions	15	15.6	17	20.2	13
That the doctor discuss concerns relating to your illness and care with your family present	26	28.9	24	30.0	13
To have an opportunity to strengthen or maintain relationships with people who are important to you	33	32.4	36	36.7	12
To be able to contribute to others (gifts, time, knowledge, experience, etc)	20	20.0	16	17.4	12
To be treated as an individual with unique needs, values and preferences, and not just as a disease	21	20.2	25	24.0	12
To complete things and prepare for life's end (life review, resolving conflicts, saying goodbye)	30	30.0	32	34.0	11
To receive respectful and compassionate care from health care providers	22	21.0	30	28.3	10
To have your spiritual or religious needs met	13	13.3	18	26.9	10
Have a private room so that your family can be comfortable and discussions relating to your illness are confidential	16	15.1	19	22.1	9
To have a sense of control over decisions about your care	15	14.7	19	19.0	9
To have the same nurses looking after you	11	10.7	14	14.4	8
That your illness not create financial problems for your family	21	25.3	28	34.6	8
Not to be kept alive on life support when there is little hope for a meaningful recovery	61	61.0	N/A	N/A	N/A
To be able to die in the location of your choice (ie, home or hospital)	13	13.3	N/A	N/A	N/A

*Sorted from largest to smallest opportunity index (OI). Ratings: 1 = not at all satisfied; 2 = not very satisfied; 3 = somewhat satisfied; 4 = very satisfied; 5 = completely satisfied. N/A Not applicable

identify any of the components of CPR. Only one-half of patients interviewed wanted to have a discussion about life-saving resuscitation treatments with their doctor. In relation to the decision regarding whether to undergo CPR, many (42.5%) had not spoken to anyone about their resuscitation wishes, although the majority wanted some degree of shared decision making with their physician regarding CPR.

DISCUSSION

The present study aimed to identify the major opportunities to improve EOL care for patients hospitalized because of advanced HF. The high six-month mortality rate of survey participants is consistent with the poor prognosis associated with HF (15) and highlights the compelling need for EOL issues to be viewed as relevant and important aspects of care. The OI highlights several areas in which efforts to improve EOL care should be focused to bridge these gaps and implement best practices in HF management. The major opportunities for improving EOL care related to providing support for family caregivers, an adequate discharge plan, effective symptom relief and clear, honest communication with the physician(s) in charge of their care. All of these care imperatives are congruent with current guidelines from the Canadian Cardiovascular Society (16) regarding EOL care for patients who have HF. Canadian Cardiovascular Society recommendations support the need for EOL issues including resuscitation preferences to be discussed with patients following an HF diagnosis, revisited routinely and following exacerbations of illness. However, survey results clearly indicate that gaps existed between the guidelines and patient needs regarding key aspects of EOL care, with potentially serious consequences for patients and their families.

The greatest gap in the OI related to patient fears about burdening their family with increasing physical or emotional needs. Management of increasing symptoms and emergency situations, and decisions about resuscitation are known sources of caregiver stress (17). Both patients and caregivers require physical and emotional support in relation to management of chronic disease and worsening HF symptoms as EOL approaches (18). Patients in the present study clearly understood the increased levels of physical and emotional support required from their family caregivers as their symptoms increased. Not only do family caregivers require the skills and support to provide care, but patients require reassurance that adequate support is available for their caregivers.

According to the OI, another important gap identified by patients was the lack of a clear plan of care and health services available at the time of hospital discharge. An individualized advance care plan (ACP) should be developed and based on informed and shared decision making by patients to promote seamless care that bridges community and hospital settings. Gaps identified in the present study indicate that components of the ACP must include prevention and management of symptoms and emergency situations, attention to caregiver issues, and patient preferences for interventions such as resuscitation.

The OI helps to prioritize strategies to facilitate communication among patients, their family caregivers and health professionals regarding the development of an ACP. Patients want honest information about the course of HF, and the risks and benefits of treatment options, delivered in a way they can understand. Lack of information about HF has been perceived as a barrier to EOL care for patients and their caregivers in community and hospital settings (6,18,19). Issues

TABLE 2
Demographics of patients with advanced heart failure

Characteristic	Heart failure (n=106)
Age, years	75.8±9.0
Men, n (%)	69 (65.1)
Women, n (%)	37 (34.9)
Race, n (%)	
Caucasian	98 (92.5)
Other	8 (7.5)
Katz score	5.3±1.3
Living arrangements, n (%)	
Alone	40 (37.7)
Chronic care facility	1 (0.9)
Nursing home	6 (5.7)
With other family	9 (8.5)
With spouse/partner	49 (46.2)
Unknown	1 (0.9)
Location of home, n (%)	
Urban	89 (84.0)
Rural	15 (14.2)
Missing	2 (1.9)
Overall quality of life, n (%)	
Excellent	6 (5.7)
Very good	12 (11.3)
Good	24 (22.6)
Fair	24 (22.6)
Poor	33 (31.1)
Unknown	7 (6.6)
Emergency room visits in the past year	2.6±10.0
Hospital admissions in the past year	1.8±1.2
6-month mortality status	
Dead	50 (47.2)
Alive	53 (50.0)
Unknown	3 (2.8)

Data presented as mean ± SD unless otherwise indicated

related to prognostic uncertainty influence the timing of EOL discussions (18,20). However, it is under conditions of uncertainty (and precisely because of those conditions) that a care plan should be implemented that is inclusive of and responsive to EOL issues for patients who have HF. Patients have voiced a preference for such discussions to begin when they are not severely debilitated by their illness (9). Failure to engage patients and their families in discussions about EOL issues may deprive them of opportunities to consider possible alternatives, and make life and treatment decisions they want to make. In turn, a lack of communication may lead to increased dissatisfaction with EOL care and caregiver distress in the bereavement phase.

Most patients wanted some involvement in EOL decisions, yet there appeared to be a dissonance between the severity of illness, a patient's understanding of his or her prognosis and EOL choices regarding resuscitation, and the appropriate place and resources for managing distressing symptoms as EOL approaches. Either patients do not receive a clear message that EOL issues are important or relevant, or they are given the message but do not hear it. It may also be that for some, the timing of the EOL discussions is such that acute illness, decreases in cognitive function or stress may interfere with information processing and comprehension. Because ill-informed patients may not understand the relevance and thus not want to talk about EOL issues, it is incumbent on health care professionals to create and cultivate such opportunities. However, cardiac practitioners have said that they have difficulty in raising issues related to EOL (21). Failure to fully share and interpret the realities of HF, and the complexities of the treatment trajectory may deprive patients and their families of

TABLE 3
Patient perspectives on end-of-life issues

	HF (n=106)
Preference for level of care (0 = aggressive, 10 = comfort only)	6.7±3.3
Current assessment of level of care (0 = aggressive, 10 = comfort only)	5.7±3.1
Preference for location of death, n (%)	
Home	47 (44.3)
Hospital	27 (25.5)
Does not matter	26 (24.5)
Obstacles to dying at home, n (%)	
Burden	62 (58.5)
No caregiver available	23 (21.7)
Pain	32 (30.2)
Lack of health care services	51 (48.1)
Unsuitable environment	9 (8.5)
Other	6 (5.7)
Plan of care in place for emergency, n (%)	46 (43.4)
In emergency, 911 or home visit, n (%)	
911	79 (74.5)
Home visit	8 (7.5)
Other	0 (0.0)
Missing	19 (18.0)
Had discussion – how long to live, n (%)	12 (11.3)
Have understanding of how long to live, n (%)	
More than 1 year	43 (40.6)
Approximately 1 year	6 (5.7)
Approximately 6 months	4 (3.8)
Less than 6 months	6 (5.7)
Less than 1 month	4 (3.8)
Do not know	34 (32.1)
Missing	9 (8.4)
Want to know progression and prognosis, n (%)	49 (46.2)
Self-rated relevance of end-of-life issues?, n (%)	
I am currently facing them or have faced them	61 (57.5)
I am likely to face them in the next few weeks to months	6 (5.7)
I will likely face them in the next 6 months	1 (0.9)
I will likely face them in the next year	10 (9.4)
Not relevant	22 (20.8)
Missing	6 (5.7)

Data presented as mean ± SD unless otherwise indicated. HF Heart failure

compassionate and comprehensive advance care planning. A language is needed to help practitioners engage in discussions that invite shared decision making about palliative and EOL preferences and care with patients. Given the HF trajectory, the language strategy must be amenable to implementation at points across this trajectory, while delivering a consistent message that advanced planning issues are important and relevant for these patients, irrespective of the exactitudes of prognosis. The ACP would ensure that patients receive clear, coordinated and consistent messages about their illness and care options.

While EOL care constitutes more than decision making about CPR, decisions about resuscitation should be a focal point, particularly when patients become hospitalized. Given the high six-month mortality rate in this study sample and the severity of illness, the patients' lack of understanding about CPR was surprising. Clearly, if study participants had been given information about CPR, they did not articulate it during the survey interview. Informed consent is a cornerstone of health care delivery, yet our data raise questions about the information patients have about what constitutes CPR and on which they base decisions about resuscitation. It is possible that patients who have attended heart function clinics, been cared for by cardiac specialists and/or made decisions about various interventions may have different

TABLE 4
Patient perspectives on communication and decision making related to cardiopulmonary resuscitation (CPR)

Question	HF (n=106), n (%)
Have you had CPR before?	
Yes	24 (22.6)
No	75 (70.8)
Missing	7 (6.6)
Could you tell me what treatments are performed on people during CPR? (check as many as apply)	
Artificial breathing/intubation	52 (49.1)
Chest compressions	59 (55.7)
Defibrillation	21 (19.8)
Drugs	12 (11.3)
Do not know	26 (24.5)
Number of people who knew 0 or more of the above?	
Knew 0	32 (30.2)
Knew 1	23 (21.7)
Knew 2	34 (32.1)
Knew 3	15 (14.2)
Knew 4	2 (1.9)
Out of 100 patients like you, how many do you think would survive CPR and be discharged home?	
90	5 (4.7)
75	11 (10.4)
50	10 (9.4)
25	14 (13.2)
10 or less	4 (3.8)
Do not know	56 (52.8)
Missing	6 (5.6)
Have you considered what you would like doctors to do if your heart stops beating?	
Yes	58 (54.7)
No	42 (39.6)
Missing	6 (5.6)
Would you like to have a discussion with your doctor about life-saving resuscitation treatments?	
Yes	54 (50.9)
No	44 (41.5)
Missing	8 (7.5)
Who have you spoken to about your wishes concerning life-saving resuscitation treatments? (check as many as apply)	
Family member	45 (42.5)
MD treating you in hospital	28 (26.4)
Family MD	14 (13.2)
Nurse	1 (0.9)
Other	6 (5.7)
No one	45 (42.5)
Considering your current health condition, which of the following best describes your desire for information to make a decision regarding CPR?	
I would want a lot of information	39 (36.8)
I would want some information	36 (34.0)
I would not want any information	23 (21.7)
Missing	8 (7.5)
Who would you like to be involved in the decision of whether to have CPR?	
No one else other than self	20 (18.9)
Spouse/other family member	13 (12.3)
MD in hospital	12 (11.3)
Combination of family/spouse and MD	45 (42.5)
Other	0 (0.0)
Missing	16 (15.1)

TABLE 4 – CONTINUED
Patient perspectives on communication and decision making related to cardiopulmonary resuscitation (CPR)

Question	HF (n=106), n (%)
If you had to make a decision now, and were able to participate in that decision, what role would you want to have in decision making?	
Leave decision up to doctor	7 (6.6)
Let doctor decide but consider my wishes	12 (11.3)
Doctor and I share decision	35 (33.0)
I decide, consider MD wishes	21 (19.8)
I make decision myself	24 (22.6)
Missing	7 (6.6)

HF Heart failure; MD Medical doctor

perspectives about EOL issues such as CPR and defibrillation from those who have not had such experiences. We did not collect these data from survey participants and acknowledge the need to further investigate the effect of such exposures to patient understanding of CPR and other EOL issues.

Although place of death was not rated as an important item in relation to other EOL issues, many study participants preferred a home death. However, most said they would call 911 in an emergency. Implicit in a home death is a need to plan for such a possibility with family members. This raises questions about patients' and families' understandings about HF and whether, in some circumstances, a home death is a realistic goal. Anticipatory guidance about emergency situations could decrease the suffering of patients, assist family caregivers to avoid and/or manage a crisis, and better facilitate the use of scarce health care resources.

The OI indicates that participants wanted clarity about which physician was in charge of their care. It is possible that such clarity is also required among practitioners caring for these patients, particularly because patients may be referred to various cardiac subspecialties, and hospital-based, community and family physicians. In addition to prognostication issues, 'turf wars' between specialists and organizational barriers to seamless care have created obstacles for patients who have HF to receive palliative services as part of an ACP (20). Given the current resource constraints within the health care system, a system of disease-specific EOL care dedicated to HF is neither realistic nor necessary. However, there is an urgent need for practitioners involved in the care of patients who have advanced HF to work with existing EOL care networks, to engage in practical discussions with palliative and community specialists, and to integrate the needs of these patients into a system of advanced care planning that is sensitive to the realities of HF.

Given the importance of EOL issues to patients, their inclusion as key performance indicators of HF best practices would emphasize the need to address them throughout the illness continuum. The results of the present study were used to develop the Canadian Health Care Evaluation Project (CANHELP) questionnaire (22), which can be used as a quality indicator.

Limitations and strengths

The present study sample was comprised largely of Caucasian, English-speaking men and may not adequately reflect the EOL perspectives of other patients diagnosed with end-stage HF. Specifically, women, the frail elderly, those institutionalized in long-term care settings, and those of the increasingly racially and culturally diverse Canadian population were under-represented. Further studies that reflect the ethnic and racial diversity of Canadian society are required to ensure that EOL care is sensitive to the needs of various groups. In addition, because the survey was conducted in a face-to-face interview, it is possible that the responses of patients were influenced by their interaction with the interviewer and may not reflect their actual perceptions.

The present study also had several strengths. Importantly, the study documented preferences for EOL care from patients who had advanced HF in five major centres across Canada, and included urban and rural patients. Our findings reflect the perspectives of patients who were seriously ill due to HF, and from whom such rich and comprehensive data has been difficult to obtain previously. A further strength of the study is the combined qualitative and quantitative methods used to derive a questionnaire that reflected a wide variety of issues patients viewed as relevant at the EOL. The OI also provides patient-centred direction for health care providers to concentrate efforts for improving EOL care in areas in which the most impact on EOL care could be made. This is congruent with the realities of the undulating HF trajectory, HF guidelines and comprehensive patient-centred care at the EOL.

CONCLUSIONS

Advanced care planning should be part of standard care of patients who have advanced HF, yet there are strong indications that this planning is not being effectively addressed. Opportunities for improvement in EOL planning and care for patients who have HF have been identified. The results of the present survey indicate that targeted efforts to improve communication with and for patients is required to develop a system of seamless, coordinated EOL care and to address care gaps.

REFERENCES

- Levenson JW, McCarthy E, Lynn J, Davis RB, Phillips RS. The last six months of life for patients with congestive heart failure. *J Am Geriatr Soc* 2000;48(5 Suppl):S101-9.
- Johansen H, Strauss B, Arnold JMO, Moe G, Liu P. On the rise: The current and projected future burden of congestive heart failure hospitalization in Canada. *Can J Cardiol* 2003;19:430-5.
- Naylor C, Slaughter PM. Cardiovascular health & services in Ontario: An ICES atlas. Toronto: Institute for Clinical Evaluative Sciences, 1999.
- Ko D, Alter D, Austin P, et al. Life expectancy after an index hospitalization for patients with heart failure: A population-based study. *Am Heart J* 2008;155:324-31.
- Gott M, Barnes S, Parker C, et al. Dying trajectories in heart failure. *Palliat Med* 2007;21:95-9.
- Boyd KJ, Murray SM, Kendall M, Worth A, Benton TF, Clausen H. Living with heart failure: A prospective community based study of patients and their careers. *Eur J Heart Fail* 2004;6:585-91.
- Coventry PA, Grande GE, Richards DA, Todd C. Prediction of appropriate timing of palliative care for older adults with non-malignant life-threatening disease: A systematic review. *Age Ageing* 2005;34:218-27.
- Lee DS, Austin PC, Rouleau JL, Liu P, Naimark D, Tu J. Predicting mortality among patients hospitalized for heart failure. *JAMA* 2003;290:2581-7.
- Caldwell PH, Arthur HM, Demers C. Preferences of patients with heart failure for prognosis communication. *Can J Cardiol* 2007;23:791-6.
- Barnes S, Gott M, Payne S, et al. Prevalence of symptoms in a community-based sample of heart failure patients. *J Pain Symptom Manage* 2006;32:208-16.
- Goodlin SJ, Haupton PJ, Arnold R, et al. Consensus statement: Palliative and supportive care in advanced heart failure. *J Card Fail* 2004;10:200-9.
- Heyland DK, Dodek P, Rocker G, et al. What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *CMAJ* 2006;174:627-33.
- Heyland DK, Groll D, Rocker G, et al. End-of-life care in acute hospitals in Canada: A quality finish? *J Palliat Care* 2005;213:142-50.
- Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. *Gerontologist* 1970;10:20-30.
- Goldberg RJ, Ciampa J, Lessard D, Meyer TE, Spencer FA. Long-term survival after heart failure: A contemporary population-based perspective. *Arch Intern Med* 2007;167:490-6.
- JMO Arnold, P Liu, C Demers, et al. Canadian Cardiovascular Society consensus conference recommendations on heart failure 2006: Diagnosis and management. *Can J Cardiol* 2006;22:23-45.
- Molloy GJ, Johnston DW, Witham MD. Family caregiving and congestive heart failure: Review and analysis. *Eur J Heart Fail* 2005;7:592-603.
- Murray SA, Kendall M, Benton TF, Clausen H. Dying of lung cancer or cardiac failure: Prospective qualitative interview study of patients and their careers in the community. *BMJ* 2002;325:929-32.
- Formiga F, Chivite D, Ortega C, Casas S, Ramon JM, Pujol R. End-of-life preferences in elderly patients admitted for heart failure. *Q J Med* 2004;97:803-8.
- Hanratty B, Hibbert D, Mair F, et al. Doctors' perspectives of palliative care for heart failure: Focus group study. *BMJ* 2002;325:581-5.
- Selman L, Harding R, Beynon T, et al. Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't". *Heart* 2007;93:963-7.
- CANHELP Questionnaire. <www.thecarenet.ca> (Version current at September 29, 2009).

Patients indicated that coordinated and comprehensive advanced care planning that includes spousal and family caregiver support, symptom management, discharge planning and effective communication is fundamental to their EOL care.

ACKNOWLEDGEMENTS: The authors thank all study personnel and site investigators (see Heyland et al [13] for full details) who participated in this study at the participating hospitals: Queen Elizabeth II Health Sciences Centre, Halifax, Nova Scotia; Kingston General Hospital, Kingston, Ontario; Toronto General Hospital, Toronto, Ontario; St Paul's Hospital, Vancouver, British Columbia; and the Royal Alexandra Hospital, Edmonton, Alberta. We also extend our gratitude to the Canadian Researchers at the End of Life Network (CARENET) members, Joan Tranmer and Jim Kutsogiannis, for their comments in preparing this manuscript.

DISCLOSURE: Patricia Strachan (formerly Caldwell) was a Heart and Stroke Foundation of Ontario Post-Doctoral Fellow from 2005 to 2008.

FUNDING: National Health Research and Development Program of Canada and the Canadian Institutes of Health Research.