End-of-life planning in heart failure: It should be the end of the beginning

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Cardiovascular disease (CVD) is a chronic, progressive, incurable condition characterized by periods of apparent stability interspersed with acute exacerbations. Despite many important advances in its treatment, approximately one-third of deaths in Canada each year result from CVD. While this might lead one to assume that a comprehensive medical approach exists to the management of this inevitable outcome, the reality is much different. The current Canadian medical model emphasizes the management of acute exacerbations of CVD during which end-of-life issues figure frequently and prominently, although in a setting that is inappropriate to address the comprehensive needs of patients and their families.

As a result, end-of-life care was made a theme of the recently reported Canadian Heart Health Strategy and Action Plan (www.chhs-scsc.ca). From this, several recommendations are made, central to which is the need to reframe CVD as a condition ideally suited to a chronic disease management approach. In addition, replacement of the term 'palliative care' with the term 'end-of-life planning and care' is proposed to foster earlier and more integrated comprehensive care, which, it is proposed, denotes the provision of advanced care planning, palliative care, hospice care and advanced directives, with a focus on decision making and planning. Finally, end-of-life planning and care should be a routine part of assessment of any patient with CVD, should be reassessed whenever important clinical changes occur and should be provided in a manner consistent with relevant CVD practice guidelines.

Specifically, a Canadian strategy to improve end-of-life planning and care should focus on the following:

- Integrated end-of-life planning and care across the health care system;
- Facilitated communication and seamless care provision across all providers involved in end-of-life planning and care;
- Adequate resources in the community for end-of-life planning and care;
- Specialized training in sensitive communication and supportive care as part of core training for all members of the interdisciplinary care team;
- Measurement of key performance indicators for end-of-life planning and care; and
- Research into effective end-of-life planning and care.

Heart failure is an advanced form of CVD with very high morbidity, mortality and burden of care, making it an ideal condition for implementation and testing of interventions to improve end-of-life planning and care.

Key Words: Cardiovascular death; End-of-life care; Health policy; Mortality; Palliative care; Population health; Quality of life

La planification de fin de vie en cas d'insuffisance cardiaque : Ce devrait être la fin du début

Les maladies cardiovasculaires (MCV) sont des maladies chroniques, évolutives et incurables caractérisées par des périodes de stabilité apparente entrecoupées d'exacerbations aiguës. Malgré les nombreux progrès importants du traitement, environ le tiers des décès au Canada découlent d'une MCV. On pourrait penser qu'il existe une approche médicale approfondie pour prendre en charge cette issue inévitable, mais la réalité est bien différente. Le modèle canadien actuel fait ressortir la prise en charge des exacerbations aiguës des MCV pour lesquelles les enjeux de fin de vie ont une place fréquente et importante, mais dans un cadre inadéquat pour répondre aux besoins complets des patients et de leur famille.

C'est pourquoi les soins de fin de vie ont constitué l'un des thèmes de la récente Stratégie canadienne de santé cardiovasculaire et plan d'action (www.chhs-scsc.ca). En a découlé plusieurs recommandations, au cœur desquelles figure la nécessité de recadrer les MCV comme maladie idéale pour adopter une approche de prise en charge des maladies chroniques. En outre, il est proposé de remplacer le terme « soins palliatifs » par « planification et soins de fin de vie » afin de favoriser des soins complets mieux intégrés plus rapidement, ce qui, avance-t-on, fait foi de la prestation d'une planification préalable des soins, de soins palliatifs, de soins palliatifs dans des centres et de directives préalables des soins, en s'attardant sur la prise de décision et la planification. Enfin, la planification et les soins de fin de vie devraient toujours faire partie de l'évaluation des patients atteints d'une MCV, être réévalués lorsque des modifications cliniques importantes se produisent et être dispensés en harmonie avec les lignes de pratique des MCV.

Plus précisément, une stratégie canadienne pour améliorer la planification et les soins de fin de vie devrait être axée sur les éléments suivants :

- La planification et les soins de fin de vie intégrés dans tout le système de santé
- Les communications facilitées et la prestation homogène des soins entre tous les dispensateurs qui participent à la planification et aux soins de fin de vie
- L'accessibilité aux ressources pertinentes dans la collectivité pour la planification et les soins de fin de vie
- Une formation spécialisée sur des communications sensibles et des soins de soutien dans le cadre de la formation de base de tous les membres de l'équipe soignante interdisciplinaire
- La mesure des principaux indicateurs de rendement pour la planification et les soins de fin de vie
- La recherche sur la planification et les soins de fin de vie

L'insuffisance cardiaque est une forme avancée de MCV associée à un taux très élevé de morbidité, de mortalité et de fardeau des soins, ce qui en fait une maladie idéale pour adopter et mettre à l'essai des interventions afin d'améliorer la planification et les soins de fin de vie.

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“98 percent of us will die at some point in our lives.”

– from *Talladega Nights: The Ballad of Ricky Bobby*

End-of-life care is most frequently seen as synonymous with palliative care. Palliative care aims to alleviate physical, emotional, psychosocial and spiritual symptoms of patients with advanced illness, and is most often understood as applying to the care of patients terminally ill with cancer (1,2). While palliative care is increasingly seen as appropriate for patients in the most advanced stages of cardiac illness such as heart failure (HF), end-of-life care encompasses more than simply symptom management, and includes advanced care planning, hospice care and advanced directives with a focus on decision making and planning (3).

Major advances in cardiac care over the past two decades have resulted in fewer deaths from acute myocardial infarction and prolonged life for patients with heart disease (4). Heart disease often culminates in chronic HF, characterized by progressive and profound fatigue, exercise intolerance, fluid retention and breathlessness (5). These patients suffer a high degree of symptom burden, and experience disability, pain and high levels of psychiatric symptoms. The lifetime prevalence of HF is 15% to 20% for all adults, and rises sharply with age, reaching in excess of 20% in octogenarians (6). The mortality rate of HF exceeds that of many cancers, and the disease carries an equivalent symptom burden that is further compounded by an aging population (5). In the year following a first hospitalization for HF, mortality exceeds 30%, and may be as high as 60% among older patients with multiple comorbidities (5). The extreme burden on patients, their families and society makes this an ideal illness for implementation and testing of interventions to improve care. In particular, there is growing recognition for the need to improve end-of-life planning and care for patients with HF. However, the focus in cardiac care on the preservation and extension of life has led to a lack of emphasis on issues relating to end-of-life care in both the clinical and research environments.

The Senate Subcommittee to Update “Of Life and Death” stated in its 2000 report (7), “Quality end-of-life care must become an entrenched core value of Canada’s health care system”. However, it also reported evidence of uneven provision and limited access to end-of-life services, and lack of coordination for appropriate education and training in end-of-life care for members of interdisciplinary health care teams.

THE CANADIAN HEART HEALTH STRATEGY AND ACTION PLAN

In 2006, the Federal Minister of Health commissioned a comprehensive, independent, stakeholder-driven Canadian Heart Health Strategy and Action Plan, whose mandate was the development of a pan-Canadian heart health strategy to prevent and address cardiovascular disease (CVD) in Canada. The strategy, released in early 2009, combined recommendations from several critical themes, including those from a working group on timely access to quality chronic disease management and end-of-life planning and care (www.chhs-scsc.ca). The working group reviewed the current literature and care environment, and their recommendations form the basis for the report. Central to this strategy was the understanding that care for chronic CVD would be best delivered in an interdisciplinary fashion respecting the principles of the chronic disease prevention and management model (CDM) (8,9). The basic goals of this model include the following: patient-centric, interdisciplinary approach; patient care in home and primary care setting where possible; patient empowerment and collaborative care planning; and a proactive approach to prevention rather than crisis management. Critical to the proper functioning of this model is seamless communication among team members. Principles of CDM, which move care and prevention ‘upstream’ in the health care continuum, have been shown to be cost effective and to improve the health status of individuals and populations (10). With increasing

recognition that chronic diseases should be managed using a team-based CDM, the opportunity arises to address the inevitable end-of-life care in a proactive, transparent and integrated manner, and allows an overall care plan to be in effect. The alternative is to delay care planning until the advent of an emergency, with little time for consideration, which is the prevailing situation for most adults with CVD at present.

WHAT HAS BEEN DONE SO FAR?

Several projects have been commissioned in Canada. These include the Pallium project (an ongoing nationally funded project with a primary emphasis on standards of professional development, curriculum and practice tools), the Federal Ministry of Health initiative, which was implemented to evaluate the state of palliative and end-of-life care in 2002 and to make recommendations, and a Canadian multidisciplinary end-of-life research working group (Canadian Researchers at the End-of-Life Network [CARENET]) formed with funding from the Canadian Institutes of Health Research. Several single groups based primarily in the United States (3) and the United Kingdom (11,12), have performed excellent work in palliative and end-of-life care, and are beginning to address the population with HF. In particular, the United Kingdom national program for improvement in HF end-of-life care has published several important manuscripts online (www.heart.nhs.uk/endoflifecare/), which include toolkits and other support tools. In addition, the Canadian Cardiovascular Society (CCS) published guidelines regarding end-of-life care as part of the 2002 guidelines for care of the elderly patient with CVD (13), and as part of its ongoing HF guidelines updates (5).

Several issues and challenges have emerged regarding the care of patients with HF. These have been identified through a review of the literature and endorsed by feedback from various stakeholders, and include disease-specific, systemic and resource-based issues.

WHAT HAVE WE LEARNED AND WHAT CAN WE DO?

Prognostic uncertainty and impact of HF therapy

The problem: Perhaps the most significant challenge is the prognostic uncertainty and the variable clinical trajectory of the HF condition, making discussion of patient preferences complex at best. The incidence of sudden death in HF, which can be as high as 60%, makes predicting mortality even more challenging, although the increasing use of automatic internal cardioverter defibrillators in patients with reduced left ventricular ejection fraction may attenuate the rate of sudden death (5). In part, because of this prognostic uncertainty, patients with advanced HF have been documented to possess a poorer understanding of their condition and have been less involved in decisions regarding their care (14,15).

Indeed, the 2007 study of health care use at the end of life in western Canada (16) revealed variations in care suggesting that an integrated, systematic approach to end-of-life care does not yet exist. Such an approach is often absent at the end of life, partly because clinicians cannot accurately predict when death will occur, as is the case in advanced HF, and partly because of discomfort about engaging in end-of-life communication.

HF patients who do not die suddenly will deteriorate over time. However, compared with the relatively predictable disease trajectory of patients with advanced cancer, characterized by a period of preserved function followed by a precipitous decline within months of death, the disease trajectory of HF is even more highly variable, rendering accurate prediction of the time of death impractical (17,18). Therapy aimed at reduction of HF symptoms may also prolong life, or at least be perceived to do so. This may create confusion in the minds of both the patient and health care provider as to the actual goals of therapy – that the goal may be primarily to prolong life rather than primarily to alleviate symptoms (19). This may lead to the unintended expectation that other therapeutic modalities, such as mechanical device therapy or cardiopulmonary resuscitation,

may also be required, when in fact they may not be appropriate (20). HF patients are also more likely to suffer additional comorbidities, especially the elderly (21).

More importantly, the focus on predicting the timing of death detracts from the more central clinical issue of recognizing, discussing and appropriately managing patient symptoms. Patients with advanced HF often experience symptoms that are not classically attributed to HF and are less likely to be addressed by health care providers, including pain, falls, cognitive problems, mood and anxiety symptoms, functional decline, sleep disturbances and anorexia (7,9,10,22,23).

Suggested approach: While prognostication (with its very limited accuracy) may be used to help guide therapy, it should not be the sole driver of treatment goals. An approach that supports the need to engage patients and caregivers involved in decision making regarding goals of care relatively early in the course of the disease is needed. This engagement should be characterized by early and frequent communication and education, close attention to patient needs, symptoms and preferences, as well as periodic re-examination and flexible planning.

Care context

The problem: The cardiac care environment is oriented to optimizing medical management, prolonging life, and reducing or eliminating classical cardiac symptoms. There is a growing body of knowledge on the quality-of-life issues that patients with advanced cardiac disease face, especially in the presence of comorbidities, limited mobility and social isolation (3,11,24). The care context, in which 'cure' is the goal, may present an important barrier to engaging clinicians and individuals in inherently time-consuming conversations about quality-of-life and end-of-life planning and care, with which they may be far less comfortable. In addition, a review of cardiovascular deaths in one Canadian metropolitan health region suggested that few patients with CVD died at home or in hospice (J Brown, personal communication), despite evidence suggesting that 50% to 75% of patients with HF would, if given the opportunity and support, choose to die at home (25). While this may not mean we need to increase the number of patients who die at home, all patients at the end of life should have access to support and comfort in the location of their choice. Cognitive impairment, even if subtle, is common in HF patients and of particular concern because it may prevent or delay the recognition of early symptoms of decompensated HF, as well as interfere with self-management ability.

The recently reported European Society of Cardiology position statement on palliative care in HF (26) suggested several principles for setting the care context in patients with HF (Table 1). In early stages, emphasis is placed on proper diagnosis, treatment and clear communication regarding the disease, and its implications on the patient and family. This is combined with the recognition that revision of the treatment plan is required on any significant clinical change (11,26).

Suggested approach: HF management programs emphasizing self-management of comorbidities can be successful and cost effective. Transitional care interventions to facilitate hospital discharge of frail or medically complex HF patients result in fewer hospitalizations and lower costs, particularly those that promote enhanced patient and caregiver self-management skills. Caregiver involvement in the disease management process, as well as mobilization of community resources, may mitigate the impact of cognitive impairment on the course of HF. Therefore, health care systems and structures that support community-based end-of-life care in HF are needed to address the identified lack of an integrated approach.

Communication

The problem: In the United Kingdom, HF guidelines stipulate the need for good communication regarding prognosis and living with uncertainty (27). However, interviews of patients with advanced HF and their care providers identified that patients did not recall receiving material about their condition nor did they feel involved in the decision-making process about their illness (17). Furthermore, studies (28,29) have

TABLE 1

Characteristics of the three stages in progressive heart failure

Stage 1: Chronic disease management phase (NYHA class I to III)
The goals of care include active monitoring, effective therapy to prolong survival, symptom control, patient and carer education, and supported self-management
Patients are given a clear explanation of their condition including its name, etiology, treatment and prognosis
Regular monitoring and appropriate review according to national guidelines and local protocols
Stage 2: Supportive and palliative care phase (NYHA class III to IV)
Admissions to hospital may herald this phase
A key professional is identified in the community to coordinate care and liaise with specialist heart failure, palliative care and other services
The goal of care shifts to maintaining optimal symptom control and quality of life
A holistic, multidisciplinary assessment of patient and carer needs takes place
Opportunities to discuss prognosis and the likely course of the illness in more detail are provided by professionals, including recommendation for completing an advance care plan
Out-of-hours services are documented in care plans in the event of acute deterioration
Stage 3: Terminal care phase
Clinical indicators include, despite maximal treatment, renal impairment, hypotension, persistent edema, fatigue and anorexia
Heart failure treatment for symptom control is continued, and resuscitation status clarified, documented and communicated to all care providers
An integrated care pathway for the dying may be introduced to structure care planning
Increased practical and emotional support for carers is provided, continuing to bereavement support
Provision of and access to the same levels of generalist and specialist care for patients in all care settings according to their needs
<i>NYHA New York Heart Association. Adapted from reference 11. Data from references 11 and 26</i>

shown that there is poor patient and physician congruity regarding advanced care preferences and that the goal of therapy may change over time. Data from the HF cohort in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (30-32) reported that up to one-third of inpatients would have desired a discussion of treatment preferences and end-of-life care had they been given the opportunity by their care providers. Failure to discuss prognostic possibilities with patients and their families may impede patients' access to end-of-life planning and care (31,32).

Suggested approach: A need exists for sensitive provision of information and ethnoculturally appropriate discussions regarding end-of-life issues with patients and their families. Furthermore, patients with cardiac disease and their families will benefit from the education of health care providers on 'the art of how to talk about' the end of life. Communication of patient preferences among members of the health care team is paramount to ensure the patient's choices are considered regardless of who is involved in the patient's end-of-life planning and care. Patient preferences and discussion of end-of-life issues should be clearly documented on the medical record. Use of electronic health records with shared access will further facilitate seamless communication across the continuum.

Interdisciplinary approaches

The problem: As attention to end-of-life planning and care increases, specific disciplines are beginning to address the issues according to their interest. These include, but are not limited to, medicine, nursing, spiritual care, social work and other professions. Indeed, silos may even develop within professions (such as cardiovascular medicine, family medicine, and internal and geriatric medicine). There is a risk that

silos of disciplines will form, each addressing end-of-life planning. This presents the possibility of a significant challenge regarding integration and consistency of approaches to care.

Suggested approach: Respective professions and specialties should work together to establish linkages to promote the sharing of information about the diverse and complementary care options available for patients with advanced illness and, therefore, improve continuity of care. To deliver more equitable and accessible care for patients with advanced CVD, it may be helpful to build capacity among primary care providers, including generalists and advanced practice nurses, with support from specialists. This approach is consistent with the CDM (8).

Knowledge gaps

The problem: Research and evaluation are needed to increase the evidence base for end-of-life planning and care in HF. There is a lack of data collection, surveillance and ongoing monitoring to provide new insights and encourage researchers to develop strategies for end-of-life planning and care. While some evidence is emerging (33), studies are needed surrounding the effectiveness of symptom identification and management in patients with advanced HF, and the content and process of discussions about disease progression and symptom management. We need a better understanding of when, how and where patients should plan for and receive end-of-life planning and care. Analysis of demographic, geographical, ethnocultural and other variables will lead to better matching of patients to interventions, and improved counselling of patients and families.

Suggested approach: Research and development of innovative approaches to end-of-life care need to be created and fostered. Examples include the recently completed CARENET collaborative, a nondisease-specific research network. Health Canada's Secretariat on Palliative and End-of-Life Care can further inform the use of consistent definitions and terms across disciplines. Emphasis on end-of-life care and planning should be included as integral components of third-party research funding.

Professional education

The problem: Appropriate education and training are crucial for all members of the interdisciplinary team working with HF patients – including physicians, nurses, pharmacists, social workers, other health professionals and pastoral caregivers. Several universities and community colleges in Canada presently offer end-of-life planning and care training programs. They range from undergraduate or graduate degree programs, individual courses relevant to palliative care as part of a larger faculty program, or certificate programs that may have a variety of mandatory multidisciplinary courses. Despite the above, the health science community is not sufficiently coordinating its training resources for the care of those dying from CVD.

Suggested approach: Develop a mandatory curriculum (for all relevant professions) on end-of-life planning and care of patients with advanced CVD. Particular emphasis on sensitive and effective communications, cultural considerations, as well as on the management of complex comorbidities and effects of aging should be made. These approaches are consistent with the recently published report "Family Physicians and Other Specialists: Working and Learning Together", a joint report by the Royal College of Physicians and Surgeons of Canada and the College of Family Physicians of Canada (34).

Guidelines for care

Interestingly, only one of five major HF guidelines publications (the 2006 CCS consensus conference on the management of HF) (5) provides recommendations for end-of-life issues, even though HF is known to be a progressive, incurable condition (Table 2). Only one of many general cardiovascular care guidelines – the 2002 Canadian consensus report on the care of the elderly patient with CVD (13) – provides a section regarding end-of-life and quality-of-life issues in elderly patients with heart disease (Table 2).

In these two documents, several key and consistent recommendations for the care of such patients are provided with background data

and levels of evidence – the only peer-reviewed recommendations of this type for patients with CVD in existence. The CCS has made this a major priority for current (ongoing HF guidelines implementation program) and future cardiovascular initiatives. As an example, a planned HF benchmarking initiative will review critical performance indicators and could include important end-of-life performance indicators (see below and Table 3).

Suggested approach: Leading organizations, such as the CCS, the Public Health Agency of Canada, national accrediting agencies and others should continue to develop and promote standards of care and access, which will form a framework for current and future planning of health care delivery.

Ethical considerations

The problem: Ethical guidelines, in conjunction with clinical practice guidelines, are essential to quality end-of-life planning and care. Ethical guidelines, based on the inherent dignity and worth of the individual, provide a base for actions within a specific cultural and religious structure.

Suggested approach: Incorporation of ethical principles in professional training in end-of-life planning and care will promote integration of ethical decision-making frameworks. An example might be inclusion of ethical issues as a standing item of discussion during periodic multidisciplinary case discussion, or creation of capacity for ethicist/team consultation for difficult or unusual cases.

Resource issues

The problem: Approximately one-quarter of the total deaths in Canada are related to cancer, but patients with cancer account for more than 90% of patients receiving palliative or end-of-life care (2,35,36; and J Brown, personal communication). Currently, almost one-third of deaths in Canada are due to CVD and trends in the prevalence of risk factors suggest that this will increase. However, there is an absence of equivalent resource investment in end-of-life programs, palliative care facilities, home care and equipment support, and no designation of end-of-life planning and care as a core service with a specific budget, although recent evidence suggests a slight increase (J Brown, personal communication). Without this support, patients seeking these services will need to seek hospital admission, at greater cost and reduced quality of life. Programs restricted to patients with a certain level of symptom burden and/or a predicted life expectancy do not correspond to the circumstances and needs of patients with HF. Support of caregivers is another essential resource consideration. Family members who leave their jobs to care full time for a dying relative may require income assistance or job security, especially if for an unpredictable and often protracted period of time.

Suggested approach: While recent changes supporting caregivers have occurred, such as the Canadian employment insurance program's compassionate care program, which provides benefits for up to six weeks over a period of six months to cover time spent caring for a dying relative, these are not enough. Adequate support of the patient at end of life will reduce the caregiver burden associated with this period. Significantly, the prognostic uncertainty and slow deterioration interrupted by acute exacerbations in chronic HF, may present challenges to accessing these benefits or to providing adequate coverage of what may be a protracted illness. Integration of respite care, and the development of virtual and practical supports for caregivers (such as telephone- and Internet-based networks) may help to alleviate the suffering of both patients and their families. Reconsideration of the inclusion criteria that allows patients easier access to palliative care is required. With these changes in mind, increased overall resource allocation will be required.

SPECIFIC INTERVENTIONS

A national strategy that is consistent with quality end-of-life planning and care, and compatible with the patient-centric chronic care model is required to move end-of-life planning and care forward in

TABLE 2
Canadian Cardiovascular Society (CCS) guidelines for end-of-life and palliative care

Recommendations from the 2006 CCS heart failure guidelines (5)	Grade of evidence
1. Patients with heart failure should be approached early in the heart failure disease process regarding their prognosis, advanced medical directives and wishes for resuscitative care. These decisions should be reviewed regularly and specifically after any change in the patient's condition	Level I, grade C
2. Substitute decision maker (proxy) should be identified	Level I, grade C
3. Where possible, a living will should be discussed with patients to clarify wishes for end-of-life care	Level I, grade C
4. As patients near the end of life, physicians should readdress goals of therapy – balancing quantity and quality of life, with a shift of focus to quality of life. Palliative care consultation should be considered	Level I, grade C
5. Psychosocial issues (eg, depression, fear, isolation, home supports and need for respite care) should be re-evaluated routinely	Level I, grade C
6. Caregivers of patients with advanced heart failure should be evaluated for coping and degree of caregiver burden	Level I, grade C
Recommendations from the 2002 CCS care of cardiovascular disease in the elderly guidelines (13)	
1. There is no established 'best' approach to end-of-life issues in the elderly cardiac patient. This includes the setting of appropriate end points – the end point of 'successful no codes' achieved is not satisfactory	
2. All elderly patients with cardiovascular disease need to clearly understand their illness and prognosis (including uncertainty). Patient expectations regarding outcomes of medical care should be ascertained and corrected if necessary. Every effort should be made to communicate this information effectively	
3. When appropriate, family members or loved ones should be part of the decision-making process	
4. Patient desires and discussion of end-of-life issues should be clearly documented on the medical record. Physician opinions regarding treatments should also be clearly documented	
5. Patient desires and attitudes regarding end-of-life issues should be periodically reviewed and updated on the medical record	
6. End-of-life issues should be reviewed whenever there is an important change in the patient's clinical status	
7. Research in the quality-of-life and end-of-life genres in the elderly patient with cardiac disease is urgently needed	
8. Education in ethical theory and models of ethical decision making should continue to be promoted for physicians and interdisciplinary teams involved in the care of elderly patients with heart disease. Such learning could occur at entry- and continuing-education levels	
9. Evaluation for treatment withdrawal needs to include the patient's physiological status, personal wishes, cultural and spiritual beliefs, and overall quality of life. The evaluation should be done with input from the patient's family and other health care team members	
10. The formal use of an ethical decision-making model, as well as the assistance of an ethics consultant and/or an ethics committee, can assist in the determination of a value-based course of action for complex cases	
11. Up-to-date and comprehensive levels of care and do-not-resuscitate policies (or protocols or guidelines) ought to be available in acute care, long-term care and community health care agencies	
12. Exercise caution in using the term 'futility' in discussions with patients, families and health care providers. Be aware that seemingly unreasonable requests by patients and/or families for treatment usually arise from unresolved grief and loss of trust in the health care team	
13. Physicians and other health care providers ought to become familiar with their own province's or territory's legislation (or lack thereof) on advanced directives. Where appropriate and legally binding, advanced directives (including living wills) should be respected	
14. Discussions with patients and families about advance directives should occur in the family physician's office as part of regular visits, and/or with specialists before considering new interventions (eg, heart surgery)	
15. Documentation of the patient's instructions and choice of proxy should be made available to acute care, long-term care and community facilities when they are involved in the patient's care	

Canada. When implemented, the following recommendations will lead to end-of-life planning and care that is fully integrated into all levels of cardiovascular management.

1. Implement the 2006 CCS recommendations (Table 2)

Endorse the recommendations regarding ethical, geriatric and end-of-life issues from the 2006 CCS consensus conference on the management of HF and the 2002 Canadian consensus report on the care of the elderly patient with CVD. Implementation of these recommendations will ensure that supportive care planning is incorporated into all phases of cardiovascular and HF management programs, and delivered in a patient-centric, socially and culturally sensitive manner.

2. Implement key performance indicators (Table 3)

Identify and measure key performance indicators with specific targets to assess how effectively the 2006 CCS guidelines on end-of-life planning and care are being implemented. Consistent collection of performance indicators and analysis of information about end-of-life planning and care, and the quality of care received by patients and their families, would support evidence-based decision making, service

development and system accountability. A critical success factor will be the consistent coding of patients receiving end-of-life planning and palliative care services across care settings, to ensure timely and accurate tracking of information.

3. Enhance health system capacity

Augment existing services and create new capacity for quality end-of-life planning and care to achieve the key performance indicator targets, which should include the following:

- Implement a comprehensive knowledge translation strategy for current care providers and new health care professionals on end-of-life planning and care. This should include a curriculum on timely and sensitive patient and family communication for all health care disciplines.
- Develop an electronic patient health record, or suitable alternative, containing information on patient wishes regarding level of care and supportive care preferences, and the health care team's decision making surrounding care, to facilitate communication and seamless care provision.
- Fund research on issues relating to end-of-life planning and care in heart disease.

TABLE 3
End-of-life planning and care – indicators

Potential key performance indicators

Percentage of heart failure patients who have a documented advanced care directive
Percentage of heart failure patients who have a proxy decision maker identified
Percentage of heart failure patients who have a documented discussion on resuscitation preferences
Number of reviews and revisions to a patient's advanced care directive
Percentage of heart failure patients receiving palliative care or a palliative care consult
Percentage of palliative care and hospice patients who have heart failure
Percentage of heart failure patients who have a documented assessment of caregiver needs
Measures of quality end-of-life planning and care: <ul style="list-style-type: none"> • patient- and family-centred decision making; • communication about disease course and care plan; • continuity of care; • emotional and practical support; • symptom management and comfort care; • spiritual support; and • caregiver well-being
Measure of family/patient satisfaction
Research funding in Canada directed to end-of-life planning and care in heart disease
Percentage of postsecondary curricula that include education in end-of-life planning and care
Percentage of professional licensing examination questions that relate to end-of-life care and ethical decision making
Percentage of heart failure patients who die in their place of preference

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- Allocate resources to increase provision of adequate and comprehensive end-of-life care in the community, including home care and primary health care support.
- Develop end-of-life strategies that meet the unique needs of Aboriginal/indigenous people and other ethnocultural groups that address their unique challenges in accessing quality end-of-life care, and their distinctive expectations, rituals and desires relating to dying and death.

CONCLUSION

Currently, the Canadian model of care for chronic CVD does not adequately address the subject of end of life. The recent Canadian Heart Health Strategy and Action Plan document provides a comprehensive blueprint for enhanced prevention and care strategies for the patient with CVD. This paper outlines several key suggestions including a change in terminology to 'end-of-life planning and care' and its integration into the routine management of CVD according to chronic disease management principles. Increased focus on this area in terms of health care planning, research and resource allocation are also central to our suggested approach. We recommend adoption of existing relevant Canadian guidelines such as those published by the CCS and formation of key performance indicators as well as an adequate measurement system to gauge quality. It is our hope that with implementation of these recommendations and follow-up by measurement of key performance indicators, we can provide the very best care to our patients and family members when they need it most.

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