

## **La gestion des soins palliatifs prodigués aux adultes atteints d'insuffisance cardiaque à un stade avancé**

**Sharon Kaasalainen, Patricia H. Strachan, Kevin Brazil,  
Denise Marshall, Kathleen Willison, Lisa Dolovich,  
Alan Taniguchi, Catherine Demers**

Notre étude visait à étudier le déroulement de la prestation des soins prodigués à des adultes résidant dans la communauté, mourant d'insuffisance cardiaque à un stade avancé, à la lumière de l'expérience des patients, des proches aidants et des prestataires de soins. Un plan d'analyse descriptive et qualitative a servi à guider la collecte, l'analyse et l'interprétation des données. L'échantillon comportait 8 patients, 10 proches aidants, 11 infirmières, 3 médecins et 3 pharmaciens. L'analyse des données révèle que certains facteurs contextuels particuliers influent sur la prestation des soins palliatifs (soit le modèle de soins palliatifs en matière de cancer, l'accès limité aux ressources et les difficultés relatives à la pronostication). Les patients ont décrit le choix des interventions et le fait de composer avec la fatigue, la douleur, la dyspnée et la perte d'autonomie. Les proches aidants ont parlé de surmonter le fardeau de la prestation des soins et de la foi qui les soutenait. Les professionnels de la santé ont décrit leur rôle relativement à la coordination des soins, au transfert de compétences, à la gestion des médicaments et à l'optimisation de la collaboration interprofessionnelle. Les participants aspiraient à atteindre trois résultats : la gestion efficace des symptômes; la satisfaction à l'égard des soins; et une mort paisible.

Mots clés : soins palliatifs

# **Managing Palliative Care for Adults With Advanced Heart Failure**

**Sharon Kaasalainen, Patricia H. Strachan, Kevin Brazil,  
Denise Marshall, Kathleen Willison, Lisa Dolovich,  
Alan Taniguchi, Catherine Demers**

The purpose of this study was to explore the care processes experienced by community-dwelling adults dying from advanced heart failure, their family caregivers, and their health-care providers. A descriptive qualitative design was used to guide data collection, analysis, and interpretation. The sample comprised 8 patients, 10 informal caregivers, 11 nurses, 3 physicians, and 3 pharmacists. Data analysis revealed that palliative care was influenced by unique contextual factors (i.e., cancer model of palliative care, limited access to resources, prognostication challenges). Patients described choosing interventions and living with fatigue, pain, shortness of breath, and functional decline. Family caregivers described surviving caregiver burden and drawing on their faith. Health professionals described their role as trying to coordinate care, building expertise, managing medications, and optimizing interprofessional collaboration. Participants strove towards 3 outcomes: effective symptom management, satisfaction with care, and a peaceful death.

Keywords: access to care, cardiovascular disease, community health nursing, palliative care

## **Background**

Heart failure (HF) is a leading cause of hospitalization in older Canadians and it is predicted that the aging of the population will result in increasing numbers of those affected (Johansen, Strauss, Arnold, Moe, & Liu, 2003; Tsuyuki, Shibata, Nilsson, & Hervas-Malo, 2003). Surprisingly, HF is associated with mortality rates higher than those for some cancers (Naylor, 1999). Despite treatment, patients with advanced HF continue to report a heavy daily symptom burden (Janssen, Spruit, Wouters, & Schols, 2008). The high prevalence of distressing symptoms includes fatigue (42–82%), dyspnea (18–88%), pain (20–78%), insomnia (36–48%), anxiety (2–49%), constipation (12–42%), anorexia (11–43%), edema (33–44%), and depression (6–59%) (Janssen et al., 2008; Solano, Gomes, & Higginson, 2006). The prognosis for HF patients with advanced disease is poor. The 5-year mortality rate following a first hospitalization for HF has been reported as 68.7% with a median survival of 2.4 years (Ko et al.,

2008). A 1-year mortality rate of 40% to 50% has been reported for those who are symptomatic at rest (Pantilat & Steimle, 2004).

Patients living with advanced HF are particularly underserved in relation to end-of-life care, since the palliative care paradigm as we know it is based on a cancer model. This model bases transitions to end-of-life care and services on somewhat predictable illness trajectories, leaving individuals with advanced HF often ineligible and devoid of explicit end-of-life care (Goodlin et al., 2004; Horne & Payne, 2004).

Managing palliative care issues can be challenging for adults who live in the community, especially those who have advanced HF (Murray et al., 2002). The care of patients with advanced HF usually falls to community-based caregivers such as nurses, physicians, and pharmacists. Many community-dwelling adults with advanced HF have the additional support of informal caregivers (e.g., family members, friends, neighbours), who assist them with daily responsibilities such as activities of daily living and management of medications. However, these informal caregivers, as well as health professionals, are often faced with the daunting task of trying to care for adults with advanced HF with little support from the health-care system. Exploring the experiences of these individuals and the issues they regard as important could lead to efforts directed at improving quality of care at all levels (i.e., individual, health professional, system).

Recent research conducted in the United Kingdom has highlighted several barriers and supports related to optimal palliative care for patients who have advanced HF (Selman et al., 2007). In Canada, however, little research has been conducted in this area, particularly from the perspectives of patients with advanced HF, their family caregivers, and their health professionals. Such rich, subjective information provides early evidence that is critical to the planning of end-of-life care and to the development of care that is identified as a national health priority in the 2009 Canadian Heart Health Strategy and Action Plan ([www.chhs.ca](http://www.chhs.ca)).

The purpose of this study was to explore the processes of care and the inherent challenges that are experienced by community-dwelling adults dying from advanced HF, their family caregivers, and their health-care providers. The findings could offer solutions and future directions for research aimed at improving the management of palliative care for patients with HF in Canada.

## **Methods**

A descriptive qualitative design was used to guide data collection, analysis, and interpretation (Patton, 2002; Sandelowski, 2000). This qualitative design was appropriate for the study because it facilitated the gathering

of rich, contextual data that reflected the experiences of adults dying from HF and their caregivers. The study was approved by the McMaster University Research Ethics Board. Confidentiality agreements were obtained from those who collected, transcribed, and analyzed the data. Written informed consent was obtained from all participants prior to interview.

Semi-structured interviews were conducted with patients, informal (family) caregivers, and various health professionals (physicians, including geriatricians and palliative care specialists, nurses, and pharmacists) involved in the palliative care of patients with advanced HF in Hamilton, Ontario. Purposive and theoretical sampling were used to guide data collection and maximize those perspectives that would most clearly illuminate the process of palliative care. We collected data from multiple sources by recruiting participants with different roles in the palliative care experience (i.e., patients, caregivers, physicians, nurses, pharmacists). Purposive and snowball sampling were used to recruit participants. First, physicians and pharmacists who were members of a clinician and researcher network aimed at improving drug prescribing and use among seniors (Team for Individualizing Pharmacotherapy in Primary Care for Seniors; [www.tipsnetwork.ca](http://www.tipsnetwork.ca)) were contacted via telephone and invited to participate in the study. In addition, physicians were recruited through the Division of Palliative Care at McMaster University. Physicians and pharmacists were asked to identify any patient in their practice who (a) had advanced HF (New York Heart Association class 4 and ACC/AHA task force stage D), and (b) lived in the community. Any physician or pharmacist who had not had at least five patients with advanced HF in the previous 3 years was excluded from the study. The selected patients or their caregivers were approached by a participating physician or pharmacist and asked for permission to have their name and phone number given to the research assistant. Staff from a local Heart Function Clinic identified potential participants and contacted them for permission to have their name and phone number released to the research assistant. These potential participants were also sampled purposively and were considered eligible to participate in the study if they were diagnosed as having advanced HF (New York Heart Association class 4 and ACC/AHA task force stage D), English-speaking, and deemed, by their health professional, capable of taking part in a one-to-one interview.

The interviews were held at a location most convenient for the participants: for patients and family caregivers, either at home or at the Heart Function Clinic; for health professionals, at their place of work. A trained interviewer conducted face-to-face interviews with each of the participants using a semi-structured interview guide. Although the patients and caregivers were from the same dyad, they were interviewed separately,

one after the other. For two of the dyads, the caregiver was present during the patient interview for support in case the patient became fatigued and needed help. These interviewees were asked to relate their experiences living with HF, the patients' medical symptoms and symptom management, the roles of the various health professionals involved in care, and the supports and difficulties they experienced related to those areas. Similarly, health professionals were asked to identify their experiences of managing HF in the community, the predominant issues encountered, and barriers to and facilitators of optimal care provision. Two interviewers conducted 35 interviews that ranged from 20 to 70 minutes in length. Interview guides were adjusted to focus on various thematic areas that arose as the interviews progressed.

### **Data Management and Analysis**

All interviews were audiorecorded, transcribed verbatim, and imported into NVivo 7 for thematic content analysis. All transcripts were read and coded by two members of the research team (PS and SK) and the interviewer. Concepts that were identified as important and/or recurring were labelled, categorized, and coded (Boyatzis, 1998). Consistency checks were completed between investigators (PS and SK). Memos and reflective journals were used extensively to ensure credibility and dependability (Crabtree & Miller, 1999). Any discrepancies were reviewed by the investigators and discussed until consensus was reached. After 35 participants were interviewed, consensus was reached on the suspension of recruitment.

## **Findings**

### ***Description of Sample***

A total of 35 persons were interviewed. They included 8 patients (NYHA class 4), 10 family caregivers (7 spouses, 3 adult children), 11 nurses, 3 pharmacists, and 3 physicians from the Hamilton area. Of the 8 patients interviewed, 6 were male (75%). Patients ranged in age from 61 to 87 years (mean age =  $76 \pm 7.9$ ). Eight of the 10 family caregivers were female and ranged in age from 35 to 85 years (mean age =  $65 \pm 16.1$ ). Most participants (83%) were married. Family caregiving experience ranged from 2 to 18 years with an average of 7.6 years. Many patients and family caregivers reported co-morbid conditions such as diabetes, depression, and chronic lung disease. At least 50% of patients had implantable cardioverter defibrillator (ICD) and pacemaker combinations. Of the 17 clinicians interviewed, 11 were nurses (6 palliative care specialists, 3 cardiology specialists, and 1 community nursing consultant),

3 were physicians (2 palliative care specialists and 1 geriatrician), and 3 were pharmacists in private practice.

### ***Overview of Findings***

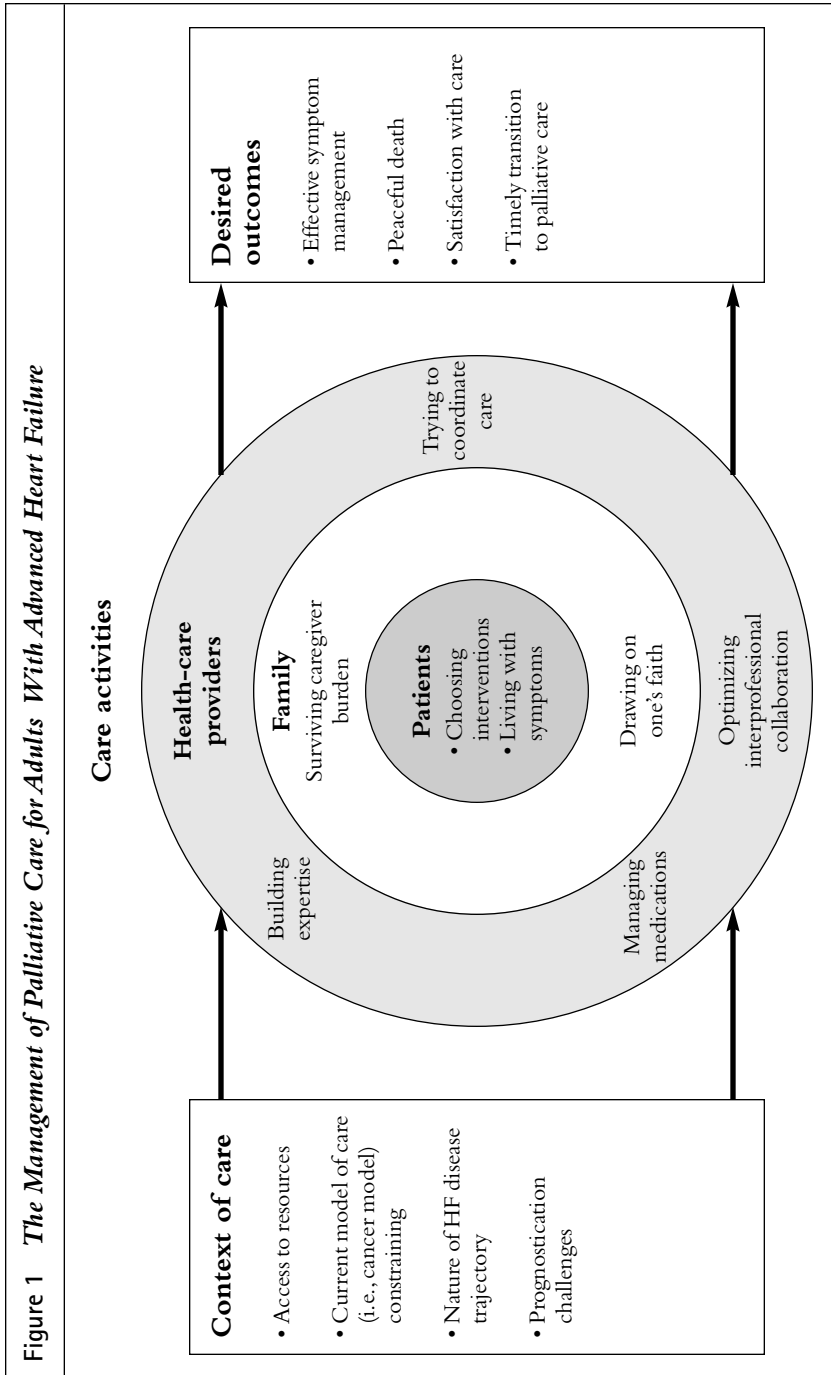
Participants described a number of activities related to the provision of palliative care for individuals with advanced HF. These care activities were influenced by contextual factors, including adoption of the cancer model of palliative care by the health-care team, limited access to resources, and prognostication challenges (see Figure 1). They were described differently by patients, family caregivers, and health professionals, and they included many challenges. Patients were challenged to choose treatment interventions and live with increasing and debilitating functional decline. Family caregivers were challenged to manage their caregiver role and to draw on their personal resources. Health professionals were challenged to coordinate care; develop HF-specific palliative care expertise; manage HF-specific medications; and optimize interprofessional collaboration between cardiac, palliative, community, and hospital care providers. All participant groups strove to achieve optimal symptom management, patient and family satisfaction with care, effective transition to palliative care, and a peaceful death.

### ***Context of Care***

Several factors influenced the care activities of patients with advanced HF. A major constraint was that the cancer model of palliative care is the only predominant model in use to manage an end-stage, non-cancer disease (HF). Participants drew contrasts between what they regarded as two types of palliative care patients (cancer and non-cancer). Individuals with HF and their family members said they were ineligible for subsidized equipment and community services, such as hospice or transportation programs that accommodate only patients with cancer. A physician concurred:

*The cancer patients have volunteer drivers, but there's a lot less access for the heart failure patients . . . there's less support groups. And the caregiver needs are very different than the caregiver needs of cancer patients.*

Health professionals delivering palliative services struggled to deal with the unpredictable nature of the HF disease trajectory. This unpredictability was dramatically illustrated in cases where patients appeared to be on their deathbed and then, after a short period, rebounded to a higher level of functioning. For example, one nurse stated, "We had one fellow who left CCU to die last January — well, he's riding his bicycle now." Due to such uncertainty, practitioners were often reluctant to transition their HF patients to palliative care, as they believed this would



involve changing the treatment regimen from an aggressive approach that appeared to make a difference to a “comfort measures only” approach. Additionally, even if practitioners felt that palliative care was appropriate for an HF patient, they encountered challenges in gauging the temporal criteria established by many palliative services, such as a projected survival time of 6 months.

In other cases, delayed referral to palliative care resulted in the palliative care team having too little time with patients and families or patients dying prior to being seen by the palliative care team. The decision to transition patients with HF to palliative care was further complicated when patients resisted the transfer. This was partially attributed to patients failing to understand or acknowledge the need for or relevance of the transfer of care or not wanting to give up their primary care team. A nurse elaborated:

*Some of the patients don't see themselves as palliative, so when we [the primary care team] bring up issues and talk about their referral to the palliative care team, they see that as a death sentence. If they don't perceive that they are dying, they don't feel the need for that referral. So we're trying to sell the palliative care team to them. And if they don't feel they need it, they're not going to take it.*

The conflict between trying to maintain a sense of hope and adopting the “palliative” designation was expressed by all participant groups. There was an overriding perception that for patients with HF there is always “one more thing [pharmaceutical or technological intervention] to try.” This belief was perceived as at odds with the commitment to a palliative approach to care.

Family members could impede the transition to palliative care, often due to their own fears and a reluctance to face the imminent death of their family member. This could make it difficult for health professionals to manage care in the most appropriate manner. One nurse illustrated this point:

*It can be the family that doesn't want to hear the conversation. There was a gentleman that was deemed palliative a year and a half ago but has been moved out of that picture a bit because his wife doesn't want to discuss that. And that's really frustrating, because we had to re-admit this gentleman a week ago and the cardiac staff are saying, “Well, what's the goal?” . . . he's still functioning in daily life, he's not bedridden, he's still able to get around and enjoy sitting on his deck and visiting with his family. The family is not to the point where they can say, “Let's just have a little bit of morphine for the dyspnea and discomfort and let's just start calling it a day” . . . And it's harder to get them to that point because you can't give*



*them a prognosis like you can with end-stage pancreatic cancer, where you've got weeks to live. We can't do that. We really don't have a clue exactly how long they'll live.*

All participant groups expressed concern about the perceived lack of continuity in care when patients were transitioning from the cardiac “community” to a palliative care service. The following comment by a family member illustrates the concern expressed by all participant groups about the transfer from cardiac to palliative care ending the patient’s relationship with cardiac care providers that had developed over time:

*There isn't a lot of continuity in your care. I don't know how it works with cancer . . . but when you read death notices it says, “Thank you very much to Dr. so and so” who treated this patient for a long time. And that's a good thing. . . . it's hard to get accustomed to a doctor and have them walk out and leave you alone. It's really difficult when you're so ill and you rely on that doctor.*

### **Care Activities of Health-Care Providers**

The majority of the health professionals interviewed identified the need to build expertise in managing palliative care for patients with advanced HF. Specifically, they expressed a lack of confidence in their knowledge about the technologies used in treating HF (e.g., ICDs) and the pharmacological and non-pharmacological treatments available to manage symptoms in this group of patients. A nurse experienced in the care of patients with cancer outlined several concerns:

*I don't have the same expertise. I don't feel as confident as I do in oncology, because I know what I'm doing [with oncology] and I know what to expect there because I've been doing this for a long time. But with heart failure I don't know the drugs as well. I know the blood work but I don't know how that prognosticates. And I don't have the same comfort with the drugs, so when I'm called in I'm thinking, is there something more we can do with the cardiac drugs? I can tell . . . with the cancer patients generally, or we send them to the cancer centre and get a blessing one way or another. So I feel a bit more hesitant . . . it feels a little outside my comfort zone.*

Nurses and physicians expressed many concerns about safety issues considering the large number of medications that patients with HF tend to be prescribed, particularly when opioids commonly used for patients terminally ill with cancer are added to the regimen of cardiac medications. A physician cited the importance of consulting the pharmacist in such a case:

*I think it's more pronounced in cardiology patients. Many end-of-life patients tend to be on a lot of medications, but cardiology patients have by far the most medications, more than cancer patients. So I think they can benefit from information and a relationship with their pharmacist and having that person or that team involved in the care, to make sure (a) that the patient is taking the medications that are prescribed, (b) that they are appropriate, and (c) that there are no interactions. There's so much greater potential for medication errors for these patients.*

Health-care providers also spoke about their attempts to coordinate care for patients with advanced HF and their family members in the midst of addressing challenges arising from changes in patients' health status. It was not uncommon for patients with advanced HF to make repeated visits to the hospital for help with their symptoms during exacerbations. Nurses often assumed a case manager role even though they were not always assigned this role, to address gaps they perceived as resulting from patients being treated by different cardiologists who rotated through the Heart Function Clinic.

Most participants described the importance of optimizing inter-professional collaboration to meet patients' needs within a holistic perspective. The interprofessional care culture was familiar to those who were members of a palliative care team. A nurse made the following comment:

*Certainly in palliative care we try to optimize quality of life for heart failure . . . they need a good multidisciplinary team that looks at things like function, things in the home, energy-conserving techniques . . . somebody they can talk to about their fears, because sudden death is such a big issue for people with heart failure. Maybe they don't need palliative care right away if they start seeing the cardiac nurse or cardiologist at the Heart Function Clinic . . . but in time we [the palliative care team], with interdisciplinary rounds, we go over cases once a month . . . then the OT says, "Well, I think I could do this with him at home," and the palliative nurse says, "Well, have you thought about this at home?" . . . maybe that kind of thing would work.*

Communication issues within the health-care system often precluded effective collaboration in the management of care for patients with advanced HF. One pharmacist provided an example:

*We're trying to encourage the physician to communicate with the pharmacist via the prescription . . . what their intentions are in terms of changing doses and stopping medications . . . I've had patients try to re-order medications that the doctors had intended to stop. I've had a family doctor try*

*to re-order medication that the cardiologist had changed. I've had a cardiologist try to increase the dose of a medication that the family doctor had changed. So I really think the pharmacist is the one that tries to communicate . . . with all of the health-care providers through the medication profile, to make sure that information is as accurate as possible.*

### **Care Activities of Family Caregivers**

Family members described the toll that their caregiving took on their physical and mental health and the challenges related to managing medications and personal care for the patient. Some of the caregivers were also struggling with the demands of managing their own chronic illnesses. They described how roles in their marriage inevitably changed as their spouse's HF worsened, leaving them to assume more responsibility for maintaining the home and family life. As a result, they became more housebound and socially isolated, with progressively fewer opportunities to engage in activities outside of the home. One caregiver described her desperate state:

*I was like a mother . . . I don't feel nothing like a wife . . . I have to support, I have to take care of everything . . . everything about the pills and how I have to look after him — it's just like a little baby and I was like a mother . . . make me so uncomfortable.*

Other caregivers described a more positive experience where they coped by mobilizing personal resources to maintain a positive outlook. Caregivers told stories of enduring commitment and dedication to their marriage despite the daily burden that they faced. One caregiver drew on her faith to meet challenges arising from her role:

*It's just become part of our life that has to be done. If he needs something and I'm reading, then that's fine. If it can wait for a few minutes then it does, but if it has to be done then it has to be done. Like, right now I have to help him shower and I make up his needles and I help him take his needles . . . and he doesn't do much walking on his own so he takes my arm, even in the house. He's got extra dizziness right now because of the added medication, but even if we go out from the car he's always got my arm. But really, when you think of what some other people have to deal with [in] caregiving, my load is light . . . we just take it day by day and have a lot of faith. I have strong faith and that helps me. And as a friend of ours said — because they're going [through] the same type of thing — he said, "Well, we got married 50-some years ago and this was our commitment and that's it." And I say, "That's how I feel too."*

### **Care Activities of Patients With Advanced HF**

The challenges for patients with advanced HF included choosing medical interventions (medications, surgical procedures, and technological interventions such as an ICD) and living with symptoms (fatigue, shortness of breath, pain, and functional decline). Most patients intended to “fight to the bitter end,” with the primary goal of extending their life for as long as possible. One nurse provided an example of this approach:

*One gentleman who is on morphine . . . we just brought up the discussion about when do you want your defibrillator turned off and he was really offended by this . . . so we just try to touch on issues . . . Another lady was young but her defibrillator kept going off over and over again, to the point where she wore out the battery in 8 months and it's supposed to last for 8 to 10 years . . . We asked her if we should put in a new one and she didn't even think twice. She said, “Of course, if I don't have it I'm going to die. Every time it [the ICD] goes off it brings me back, so it's doing its job.” So they spent \$25,000 and put in a new one and she lived only 2 months after that . . . she just assumed she would see her grandchildren one day.*

A challenge of working with cardiac patients was the nature of their symptoms, in particular “the acuteness of the shortness of breath, which sometimes can be much more unbearable than actual pain . . . shortness of breath and a feeling of suffocation.” One nurse explained that “you have to treat pain differently [from] what you're accustomed to, because it's not a persistent pain like you'd see in cancer patients.” Fatigue was viewed as most troubling in the home setting due to the limitations of known effective treatments. A patient described his challenge of managing prevailing symptoms:

*I've had everything — you name it. I've had lots of angina, lots of bloating — that's one of the reasons that I'm on dialysis . . . I've been in the hospital at least 10 times . . . I've had 3 heart attacks, I have a pacemaker, defibrillator, and now I have kidney failure. I'm a diabetic . . . so I've had every symptom you can think of . . . I take [nitro spray] to bed with me because during the night I get so flustered . . . I was thinking about it last night and I thought, when I get this weak feeling I know that this side of me isn't right [points to left side of chest] . . . so I get this out and I lie with it in my hand and I elevate my bed and take [cardiac medication] and it saves me going all the way to the bathroom, but of course I have to get up and down to the bathroom all night anyway because I'm getting rid of the fluid.*

### **Desired Outcomes**

A number of key desired outcomes of palliative care were identified by participants — specifically, effective symptom management, satisfaction with care, and a peaceful death. All of the participant groups stated that their primary goal was to achieve effective symptom management, with pain and dyspnea as the two most common foci. One nurse elaborated:

*I think the goal at that point is to keep them at home and [let them] die comfortably . . . The biggest concern is the feeling of dyspnea — that really unpleasant feeling of shortness of breath that gets worse and worse. So if we're in a true palliative care mode, we're trying to keep the fluid balance a little more in check, but it's more the symptoms . . . you're trying to keep them comfortable.*

In addition, health professionals hoped that patients and family members were satisfied with the care being provided to them and that their needs were being met. However, they often faced many challenges in trying to achieve these outcomes — challenges that stemmed from the environment and the system as a whole.

Health professionals and patients also described a desire for a timely and smooth transition to palliative care. In most cases, patients and their caregivers stated that they had hoped to be better prepared for the discussions about transitioning to palliative care. One man described some of his experiences and wishes during the transition:

*I guess the doctors were telling me there wasn't much they could do for me any more. I guess that's when it really hit me that the old heart could stop any time now . . . But I think just sitting down — when you're feeling good and when you don't have any pain and that kind of stuff, if they sat down and slowly brought the subject to a head. I think that would have been better than just coming right out with it, especially when you weren't feeling well. But just the other day I was at the heart clinic and they said there were still things they could do for me . . . that's what they're saying now, that there's still something that they can do.*

### **Discussion**

The findings from this study highlight the vulnerability of those adults who are dying from advanced HF and their family caregivers, and the misalignment of current end-of-life services in a Canadian community and the needs of palliative patients with HF. Notably, the strongest influence related to the inadequacy of the current model of care for those individuals who are dying from advanced HF is that most palliative services are based on the traditional, cancer model of care provision.

A number of contextual factors predisposed HF patients to suboptimal or even non-existent palliative care (see Figure 1). The desired outcomes common to all three participant groups provide a consensual, positive, and client-centred basis for changes to the health-care system.

The findings indicate that challenges to achieving these desired outcomes of care were related to coordination of services within the health-care system. The traditional cancer model of care does not meet the needs of those individuals who are dying from a disease other than cancer — in this case advanced HF. Under this model, patients with advanced HF often find themselves ineligible for community supports and services, such as hospice care and assistance with transportation, when these are dependent upon a prognosis of 3 to 6 months. Of particular concern are those patients with HF who are no longer able to attend outpatient clinics for monitoring due to their declining functional status but are not eligible for palliative care in the home. There is a clear need for a new model of palliative care tailored to the needs of those with advanced HF. It has been argued that care models with a primary focus on symptom management, quality of life, and psychosocial support for patients and their families would routinely integrate a “palliative approach” to care without the need for the patient to be diagnosed as “palliative” per se (Boyd et al., 2004; Thompson, 2007; Ward, 2002).

The findings indicate that the transition from active cardiac care to palliative care is poor and disjointed. The findings are consistent with recent reports by seriously ill Canadians hospitalized with HF who identified wide gaps in their care in relation to advance care planning, symptom relief, and reduction of the emotional and physical toll on their family caregivers (Strachan, Ross, Rucker, Dodek, & Heyland, 2009). The transition to palliative care is complicated by the fact that there is often “one more thing to try” with respect to prolonging life, as opposed to focusing on optimizing the quality of the patient’s remaining weeks or months (Hauptman & Havranek, 2005). When palliative services are not available and aggressive cardiac care continues, serious issues may occur. For example, the opportunity to achieve symptom relief and a meaningful closure of life may be missed (Jaarsma & Levanthal, 2002). Interestingly, Heyland et al. (2006) found that seriously ill patients and their family members felt it was extremely important that they be able to “complete things and prepare for life’s end — life review, resolving conflicts, saying goodbye” (p. 4). Patients with advanced HF are unlikely to have this opportunity given their unpredictable disease trajectory and the constraints of the current model of care.

Most of the health professionals interviewed for the study commented on the need to introduce palliative care earlier in the disease process so that patients can be prepared well in advance, thus alleviating

the pressure to “find the right time” to talk about death and dying. This kind of discussion should be ongoing so that patients and their families will have access to palliative services when needed to promote continuity of care and will have time to develop a trusting relationship with their care providers. Murray et al. (2002) propose a dual approach to care for patients with HF, with active management being continued but the possibility of death being acknowledged and discussed. This would call for an interprofessional approach and a focus on symptom management. However, Hauptman and Havranek (2005) state that “an interdisciplinary approach has been relatively slow to reach the care of advanced HF, because there has been little tradition and experience with this approach among cardiologists” (p. 375). Thompson (2007) argues that models of care should “take account of strategic planning across primary and secondary care sectors, involve healthcare and social care services and specialist palliative care providers, and be informed by the needs, experiences and preferences of patients, carers and health professionals” (p. 901). Thus continuity of care may be better facilitated within a more coordinated approach.

Participants also spoke of the need for adequate case management for the HF population. In this study community, nurses often assumed such a role in the hospital, particularly in the Heart Function Clinic. In addition, pharmacists played an important role in medication management, as the transition from aggressive therapy to palliative care is complicated by the need to manage side effects with a combination of medications that many health professionals are unaccustomed to and uncomfortable with. Pharmacists are also well positioned to help manage and oversee the transition from hospital to community and from one physician to another. Finally, given the fatigue, functional impairment, and caregiver burden that accompany advanced HF, pharmacists may be able to assist with transportation issues around having prescriptions filled. Such services ought to be not only available but also communicated to patients dying from HF and their family caregivers, to prevent unnecessary stress and fatigue.

There is a clear need for a model of care that is responsive to the health contexts of cardiac patients. The importance of a coordinated approach to care for these individuals cannot be overstated. Murray et al. (2002) propose that the deployment of cardiac nurse specialists might reduce the number of hospital admissions and improve the coordination of care. Advanced practice nurses with specialties in both HF and palliative care could help to bridge gaps in care, particularly for patients living in the community. Advanced practice nurses have been shown to be effective in care coordination and consultation within the palliative care community, since they have the skills necessary to meet the unique and

diverse needs of these individuals (Froggat & Hoult, 2002; Weggel & Hamric, 1997). Innovative models that incorporate both of these specialties show positive results and indicate promising trends for the future (Daley, Matthews, & Williams, 2006; Johnson & Houghton, 2006).

Not surprisingly, patients with advanced HF and their families valued a trusting, supportive relationship with their health-care providers. This relationship was often challenged when the move away from active cardiac care meant leaving one “camp” (acute cardiac care) and being placed in another (palliative care). This transition was troubling for the patients, as it meant that they were introduced to a new set of health professionals at a time when they felt the worst and had the least amount of energy to develop new relationships. Heyland et al. (2006) found that what mattered most to seriously ill patients and their family members was that they have trust and confidence in the physicians looking after them. When HF patients are eventually deemed “palliative,” they are left feeling alone and abandoned at a time when they most need familiar, trusting relationships with health-care providers. Murray et al. (2002) found that patients dying from HF and their family members felt neither involved in the decision-making about their care nor empowered to work in partnership with professionals and that the prognosis was rarely discussed with them. Similarly, Aldred, Gott, and Gariballa (2005) found that, due to fragmented care provision, HF patients and their caregivers understood little of their condition, had inadequate discussions with health professionals, and felt that they had “no-one to talk to” (p. 119). There is a danger that the widespread promotion of self-care for HF patients will fuel this fragmentation if supports for patients and families are not in place when self-care begins to deteriorate. There is a paucity of research to support patients and families through the transitions (Riegel et al., 2009). Additionally, there is no consensus on whether a general palliative model that incorporates the needs of patients with advanced HF is better than an HF-specific model (O’Leary, Murphy, O’Loughlin, Tiernan, & McDonald, 2009).

This situation is particularly troubling given the many demands on those caring for a family member with advanced HF, which can leave one feeling emotionally and physically exhausted, as described in vivid detail by the participants in the present study. Brannstrom, Ekman, Bowman, and Strandberg (2007) found that caregivers were constantly worried and that caregiving was a 24-hour commitment with many life-threatening moments and many “ups and downs.” In fact, Weller Moore (2002) describes caring for a family member with advanced HF as “surviving chaos.” Caregivers not only are responsible for performing household tasks and providing physical care that keeps them indoors most of the time, but many are struggling with declining health and serious



health problems themselves (Aldred et al., 2005). Despite these caregiver challenges, there are no published research interventions designed to alleviate caregiver burden in the HF population (Lorenz et al., 2008).

This study has its limitations, including a voluntary sample based in one particular region. Therefore, the findings may not be transferable to other settings or populations. Research using a more rigorous design, such as grounded theory, could further explicate the themes and/or validate the model. Also, the sample of health professionals was limited in scope. Future research should include other important members of the health-care team, such as social workers, rehabilitation therapists, and chaplains.

In summary, the findings from this study highlight the inadequacies of the health-care system in meeting the needs of community-dwelling adults dying from end-stage heart failure and their family caregivers. In addition to increased continuity of care and a focus on symptom control and family support, patients with advanced HF and their family members would greatly benefit from an interprofessional approach to care, which is another hallmark of palliative care (Higginson & Addington-Hall, 2001; Murray et al., 2002). A profound understanding of these issues is critical to meeting the palliative care needs of community-dwelling patients with advanced HF and their caregivers. The findings suggest that a coordinated interprofessional approach that bridges hospital and community care, cardiac subspecialties (including HF), and palliative care expertise is required to meet the needs of patients with advanced HF living in the community and their caregivers. This information could inform the design and implementation of supportive networks and interventions for adults with advanced HF and is consistent with national recommendations ([www.chhs-scsc.ca](http://www.chhs-scsc.ca)). In turn, undesirable outcomes such as morbidity, caregiver stress, and hospitalizations can be minimized.

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*Sharon Kaasalainen, RN, PhD, is Associate Professor, School of Nursing, Associate Member, Division of Palliative Care, Department of Family Medicine, and an Ontario Ministry of Health and Long-Term Care Career Scientist, McMaster University, Hamilton, Ontario, Canada. Patricia H. Strachan, RN, PhD, is Assistant Professor, School of Nursing, McMaster University. Kevin Brazil, PhD, is Professor, Department of Clinical Epidemiology and Biostatistics and Division of Palliative Care, Department of Family Medicine, McMaster University. Denise Marshall, MD, is a palliative care physician and Associate Professor, Division of Palliative Care, Department of Family Medicine, McMaster University. Kathleen Willison, RN, MSc, is Assistant Clinical Professor, School of Nursing, and Associate Member, Division of Palliative Care, Department of Family Medicine, McMaster University. Lisa Dolovich, BScPhm, PharmD, MSc, is Research Director and Associate Professor, Department of Family Medicine, McMaster University; and Scientist and Associate Director, Centre for Evaluation of Medicines, St. Joseph's Healthcare, Hamilton. Alan Taniguchi, MD, is a palliative care physician and Assistant Clinical Professor, Division of Palliative Care, Department of Family Medicine, McMaster University. Catherine Demers, MD, MSc, FRCPC, is Associate Professor, McMaster University; and a consultant cardiologist, Hamilton Health Sciences Heart Function Clinic.*