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Development of a practice tool for community-based nurses: The Heart Failure Palliative Approach to Care (HeFPAC)

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Abstract

Background: Patients living with advanced heart failure (HF) require a palliative approach to reduce suffering. Nurses have described significant knowledge gaps about the disease-specific palliative care (PC) needs of these patients. An intervention is required to facilitate appropriate end-of-life care for HF patients.

Aims: The purpose of this study was to develop a user-friendly, evidence-informed HF-specific practice tool for community-based nurses to facilitate care and communication regarding a palliative approach to HF care.

Methods: Guided by the Knowledge to Action framework, we identified key HF-specific issues related to advanced HF care provision within the context of a palliative approach to care. Informed by current evidence and subsequent iterative consultation with community-based and specialist PC and HF nurses, a pocket guide tool for community-based nurses was created.

Results: We developed the Heart Failure Palliative Approach to Care (HeFPAC) pocket guide to promote communication and a palliative approach to care for HF patients. The HeFPAC has potential to improve the quality of care and experiences for patients with advanced HF. It will be piloted in community-based practice and in a continuing education program for nurses.

Conclusion: The HeFPAC pocket guide offers PC nurses a concise, evidence-informed and practical point-of care tool to communicate with other clinicians and patients about key HF issues that are associated with improving disease-specific HF palliative care and the quality of life of patients and their families. Pilot testing will offer insight as to its utility and potential for modification for national and international use.

Keywords

Heart failure, palliative care, communication, knowledge translation, integrated palliative care, practice tool

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Introduction

It is increasingly recognized that patients living with advanced heart failure (HF) want and require the opportunity to receive palliative care (PC) to reduce suffering and improve the quality of life for themselves and their families.[1–4] The numbers of patients for whom such care is appropriate is growing and expected to rise dramatically in the years to come.[5] National and international guidelines now recognize PC as an appropriate intervention for patients with HF.[6–8] Yet in Canada and many other

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countries, PC usually refers to care by specialized teams and referral is often limited by a prognostic inclusion requirement ranging from 3–6 months. It is well known that the notoriously undulating and uncertain trajectory of HF has made such prognostications difficult, making it problematic for HF patients to access appropriate care that is delivered by PC teams.[2] Patient access to clinicians with knowledge of both PC and HF is limited.[9,10] This is particularly problematic in community settings such as long term care (LTC)/nursing homes in which HF is highly prevalent, where end of life (EOL) care is usually managed and delivered by nurses[11] and where many patients die from HF.[10]

In response to this situation clinicians are being encouraged to adopt a *palliative approach* for the appropriate care of persons living with progressive, chronic, life-limiting illness such as HF; this refers to the integration of PC and chronic illness management.[12] A palliative approach can be implemented by non-specialist and specialist clinicians and includes advance care planning (ACP). It integrates the fundamental principles of PC with the needs of persons with progressive chronic illness. It can be implemented at any point in the illness trajectory to effectively manage symptoms in a holistic way and support the patient and family to improve quality of life up to the time of death.[12] Hence, we also use the term palliative approach in this article: the term PC is used with regards to care provided by specialist palliative care providers. This paper describes the development of a clinical practice tool for nurses on PC teams and generalist community-based nurses to provide a palliative approach for patients living with advanced HF.

Patients with advanced HF experience decreased quality of life associated with symptoms such as breathlessness, fatigue and depression.[13,14] Their family caregivers also experience significant negative effects.[15] HF patients who are seriously ill and/or receiving PC want their care providers to be familiar with HF symptoms, treatments and to be able to talk about the illness trajectory including EOL issues.[2,16,17] However, PC nurses have significant knowledge gaps about the disease-specific symptom management and needs of patients with HF that could inform a palliative approach to care.[2,16]

Collaboration between health professionals across disciplinary lines has been noted as a challenging and necessary pre-condition for an optimal integrated palliative approach to HF.[14,18] Limited numbers of clinics have integrated PC and HF management.[10,19] Some integrated models have demonstrated positive effects on quality of life and symptom burden.[20] An optimum model to deliver integrated HF-PC has not been established although projects are underway to study it.[21,22] One such study in Sweden addresses the need for HF clinic nurses to assess and manage symptoms, ensure treatment has been optimized and that an EOL care plan is in place.[22] In that study, scales such as the Edmonton Symptom Assessment System (ESAS), and European Society of Cardiology (ESC) guidelines are being implemented to assess and treat the common issues for HF patients receiving PC. However, in this and other studies promoting nurses' integration of PC in HF, point-of-care tools that specifically integrate HF and PC concepts are lacking. Notably, no specific integrated HF-PC practice tool for use at the point-of-care could be found in the literature that incorporated HF-specific issues and HF and PC guidelines.

This knowledge translation (KT) initiative arose when nurses and their PC health teams in a region in southwestern Ontario, Canada, expressed an urgent need for assistance in learning about the disease-specific care their HF patients required. They wanted to increase their ability to provide necessary care and to communicate more effectively with the multidisciplinary team about HF-related issues. Human and economic resource constraints within the health care system made it unlikely that all patients with advanced HF could be cared for by nurses with HF expertise or by PC specialists. Nurses requested a 'hands-on' practice tool that would increase their ability to care for HF patients at the EOL.

The objective of this KT initiative was to develop a user-friendly, evidence-informed HF-specific practice tool for community-based nurses in order to facilitate care and communication regarding a palliative approach to HF care. This report is based on the results of Phase I of a two-phase KT intervention.

Methods

Theoretical framework

KT is defined as the exchange, synthesis and ethically-sound application of researcher findings within a complex system of relationships among researchers and knowledge users to improve health.[23] Five questions provide an organizing framework to guide decisions regarding how to transfer knowledge from researchers to knowledge users.[24] Specifically, decisions need to be made to determine: (a) key messages, (b) target audiences, (c) credible messengers, (d) packaging of the evidence, and (e) measurement of evidence uptake. Development of key messages is related to the question 'What should be transferred?' Clinical practice guidelines are a tool for synthesizing the best evidence for specific patient populations. Packaging of evidence refers to deliberate decisions about how to transfer knowledge to users and takes into account common barriers to the uptake of evidence. Numerous barriers and facilitators to knowledge use have been identified including lack of awareness, lack of applicability and issues with interpretation of the evidence.[25] Various methods of packaging evidence for clinicians have been developed to overcome barriers to uptake, including the

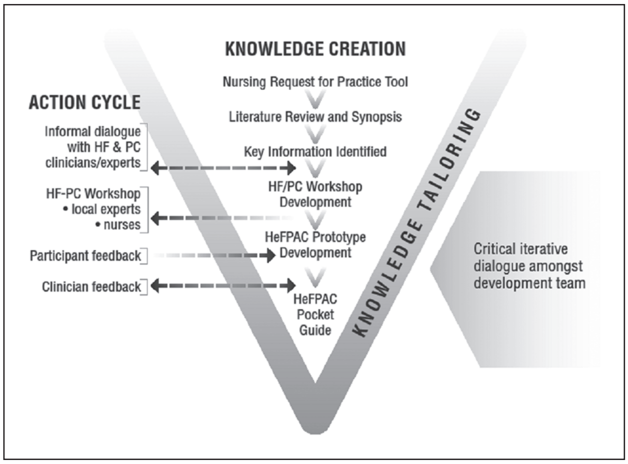

Figure 1. Adapted knowledge to action process.
HeFPAC: Heart Failure Palliative Approach to Care; HF: heart failure; PC: palliative care.

development of printed educational materials, educational meetings and outreach, use of local opinion leaders, reminder systems and audit and feedback mechanisms. Evidence on the effectiveness of KT interventions is limited despite an increase in KT science.[26]

We utilized the widely adopted Knowledge to Action (KTA) framework as described by Graham et al. in 2006. This framework guided KT activities at all phases of the project development process. According to the KTA, two phases (knowledge creation and action) occur in a fluid, non-linear and iterative way, and culminate in the creation and dissemination of customized and effective interventions.[27] Knowledge creation is viewed as a process that leads to the production of a knowledge tool. The Action cycle informs this process/tool development and is composed of the activities needed to move the tool into practice and sustain it.

Development and piloting of the practice tool

This practice tool was informed by empirical and local tacit knowledge and needs. As the KTA framework suggests, this involved moving from the knowledge creation to the action cycle at specific intervals. This ensured our response met practitioners' needs and was grounded in empirical knowledge. Figure 1 outlines this iterative process adapted for the project.

Process for identification of content

Knowledge gaps in the targeted nursing practice audience were identified. First, the development team reviewed the current health literature regarding HF-PC specific issues with the recommendations for HF-specific care in published HF and PC guidelines. Next, we held informal dialogues with HF clinic nurses, PC nurse consultants and HF and PC physician colleagues with whom community-based nurses communicated about HF-PC care issues. We asked them about issues that arose for them in practice in relation to the provision of care to patients with advanced HF.

Informed by the literature review, dialogue with clinicians and the domain and clinical expertise from nurses who work with HF and PC and nurse consultants on the project team, we developed a workshop. The workshop was based on adult education principles. It included urban and rural community-based nurses in PC and LTC contexts who were interested in providing a palliative approach to patients with HF. We engaged local HF and PC nurse and physician leaders to present key information related to HF pathophysiology, key assessments, treatments and illness management, and encouraged dialogue with and amongst participants. A case study developed to highlight key HF issues was utilized in small breakout groups to encourage critical application of new HF information and raise issues for discussion with presenters. The case study concerned a symptomatic patient with advanced HF (New York Heart Association (NYHA) Class IV). It focused on clinical reasoning related to fluid and medication management, an implantable cardioverter defibrillator (ICD) and goals of care. A 4th year nursing student made notes about the questions, comments and care issues raised during the workshop. We provided a written evaluation for participants to make further suggestions and comments about their practice needs and the mechanism by which they preferred to access that information.

Over several meetings, key areas for inclusion in the practice tool were identified. We used a distilling process of critical, iterative dialogue informed by the literature review and the dialogic and workshop data, until consensus was reached amongst the project team (CJ, JC, PHS). During the workshop, participants identified the need for a common language and terms related to HF care. There were many HF terms with which nurses were unfamiliar and which often served to limit their confidence and understanding when interacting with the HF team (for instance, NYHA classification, implanted cardiac devices). Additionally, it was identified that a mutual understanding was required amongst all care providers about the goals of care for patients with HF; the intent of HF-specific treatments (pharmacological and technologies such as ICD) and their suitability when patients were in a dying trajectory. This was a significant point of discussion between HF and PC experts in the workshop. Nurses also wanted to know about additional and user-friendly practical resources they could independently access when questions about care arose.

Content areas

Content of a practice tool was partially driven by the fact that community-based nurses said that patients with HF constituted a small and sometimes infrequent part of their caseload. They understood that key HF assessments, medications and cardiac devices known to potentially impact the patient's quality of life and dying experience were necessary to their practice. Specific signs and symptoms identified as important by HF experts were: fatigue, edema/fluid retention, dyspnea/breathlessness, pain (cardiac and non-cardiac), nausea/loss of appetite/anorexia, hypotension, tachycardia and confusion/decreased cognitive function.

Key practical tips about common medications used for advanced HF were selected. We focused on medications that are used for HF symptom control and not on medications that are intended to slow cardiovascular disease progression. It was clear from workshop participants and past experiences of HF and PC experts that nurses were very hesitant to incorporate some recommended HF medications, treatments and related assessments that they perceived to be 'aggressive' and not equated with a palliative approach. This included fluid management that involved respiratory assessments, weights and diuretic titration and the safety of administration of angiotensin converting enzyme (ACE) inhibitors and beta-blocking agents when hypotension existed. To support the application of HF-related information, nurses said a practice tool should include of a brief summary about the significance of each sign or symptom.

An explanation of the cardiac devices used in HF was needed to distinguish the function and implications of the different devices as EOL approached. Most nurses expressed confusion about the different types of implanted cardiac devices. Those who had not cared for a patient with an implanted cardiac device were unaware of the need for discussion about possible deactivation as an EOL issue. Many concerns were identified about how to integrate HF-specific issues into goals of care and ACP discussions with the family and inter-professional team. Nurses wanted assistance to incorporate these issues in ways that were consistent with a palliative approach to care.

There were also requests for the development team to select a user-friendly resource for nurses who are not HF experts, to which they could refer for additional information. Nurses were clear that HF clinical practice guidelines were overwhelmingly complex and not user-friendly at the point-of care. They wanted information to be geared for a non-specialist audience and in a format that would be easily accessible in the community setting.

Pilot testing

Utilizing adult education principles and guidance for the design of print practice tools[28] we subsequently developed a pocket guide for nurses to integrate a palliative approach to HF care. Face and content validity was established using a process of several rounds of review and feedback from nurses in the HF clinic and community PC team. To further determine if the proposed tool would meet the needs of the community-based nurses for whom it was developed, survey feedback about the content, relevance and usability of the tool for their practice was obtained from community-based nurses during a PC continuing education session. Subsequently, minor refinements were made regarding layout and terminology. Suggestions were made for maximizing access to the tool in the future.

Results

The Heart Failure Palliative Approach to Care (HeFPAC) pocket guide was developed for nurses to promote communication and clinical reasoning about a palliative approach to care of patients with advanced HF. We adopted the term 'palliative approach' to make it inclusive for HF and PC nurses and community-based nurses such as those in LTC homes for the aged and others who are not PC specialist nurses.

The pocket guide was designed for ease of use in everyday practice. In keeping with nurses' requests, it is evidence-based, simple, concise, easy to read and understand, and can be carried with them in practice settings. It was not designed to provide all of the complex information about HF. It was intended to provide key information about HF terms, assessments, treatments, medications and questions to guide clinical reasoning and important conversations with patients, their families and the inter-professional team. It is a 5.5×17 inch laminated single card, printed front and back, and accordion-folded into four sections. Font size was varied: spacing and color shading was incorporated to ease reading and increase the efficiency with which it could be used.

The pocket guide is divided into the following sections: definitions of HF, NYHA classification, and device therapies; key assessments; common reversible conditions that may exacerbate HF; practical tips about HF medications; issues for discussion with the patient and family; helpful resources for further consultation. Examples extracted from the HeFPAC are provided in Figures 2, 3 and 4.

Discussion

If the needs of patients with advanced HF are to be met, it is paramount for the nurses working with these patients to incorporate a palliative approach to their care. This presents a significant challenge both in terms of the models of care delivery and for the practical needs of the individual nurse who provides integrated care. The HeFPAC was developed in response to knowledge gaps about advanced HF that were identified by PC nurses, a group who have traditionally focused on care of patients with advanced cancer. Part of the HeFPAC uniqueness lies in that it was developed collaboratively by HF and PC nurse clinician experts and it integrates the Canadian Hospice Palliative Care Association (CHPCA) model to guide hospice palliative care with HF Clinical Practice Guidelines.[7] Additionally, the development process

Symptom/Sign	Significance	Assessment/monitoring
Edema/fluid retention	▪ Weight (wt) gain likely due to fluid retention. ▪ Wt gain of 3 lbs overnight or 5 lbs in a week is fluid weight ▪ As muscle mass is lost and fluid is retained, there may be NO obvious weight gain or loss, making weights an unreliable indicator of fluid retention as HF progresses. Sodium restriction is necessary: high salt intake can worsen HF symptoms even in end-stage illness.	Assess : wt regularly (same time of day: daily or weekly) - pants tight? - edema in the extremities: sacrum - inadvertent intake of high sodium foods (i.e. canned soups, any prepared food).
Hypotension	▪ Systolic BP < 90mmHg. is not uncommon: patient may be asymptomatic ▪ Overdiuresis is a common cause	Assess for postural BP change & symptoms of hypotension- postural dizziness, ↓ alertness or change in mental status

Figure 2. Key assessments in heart failure care.

Is there a reversible condition that may be making HF symptoms worse?.

Condition	Effects
Anemia	• Low haemoglobin worsens HF symptoms and makes fluid retention difficult to treat. **Consider transfusion** if haemoglobin < 90 mg/dl. Intravenous furosemide is required during a transfusion to manage resultant ↑ blood volume
Infection	• Any infection (eg. Urinary tract infection, pneumonia) worsens HF symptoms. **Assess for presence of infection**

Figure 3. Common reversible conditions that exacerbate heart failure (HF).

was informed by the KTA framework. Engagement of stakeholders in the development of practice guidelines is an essential element because it addresses issues of implementation and promotes receptivity, understanding and application.[29] Previously, attempts have been made to integrate PC into HF care.[10,30] This work provides the alternative and integrates HF into a palliative approach aimed at both specialist and generalist community nurses.

The HeFPAC provides a mechanism for individual nurses to provide more appropriate care, independent of major system change that would formally integrate HF and PC. Nurses requested a practice tool in the form of a pocket guide they could take with them during their care. We distinguish the tool from a 'decision aid' per se, as the HeFPAC is broad in scope and does not focus on one particular aspect of care nor a specific decision. The HeFPAC is consistent with recent Canadian recommendations to integrate HF chronic disease management with PC in Canada.[7] It offers nurses who are integrating a palliative approach, a tangible practice tool that has potential to guide appropriate assessment, communication and subsequent management regarding appropriate care for patients with HF.

It is known that community-based integrated palliation for patients with HF is associated with increased patient satisfaction and cost-effectiveness.[30] The HeFPAC offers concrete ways to begin to increase community-based nurses' capacity to integrate a palliative approach to HF-related care. The items included relate directly to common HF clinical issues that many nurses have described in their day-to-day care of patients approaching the EOL.[16,31] A common language is necessary for integrated care. In our experience, nurses were often unfamiliar with the classification of HF and its significance to treatment decisions, patient function and care. This subsequently impeded their communication and promoted a collective lack of confidence in managing patients with advanced HF and in initiating or engaging with colleagues in discussions concerning HF-specific care. While the

Have goals of care discussions occurred to:

- Plan for effective symptom relief?
- Plan for emergency situations at home (to avoid hospitalization if possible)?
- Discuss possible deactivation of the Implantable Cardioverter Defibrillator?
- Establish document and review resuscitation status?
- Assess caregiver needs?

Are home care services optimized to support required level of care and reduce caregiver demands? Consider:

- Increased home care support
- Volunteers
- Referral for long term care/hospice bed
- Palliative Performance Scale score and Edmonton Symptom Assessment System may assist in decisions for support

Figure 4. Issues for discussion with patient and family.

HeFPAC does not address all possible HF-related issues, it does offer nurses information to cross the language and expertise-related HF disciplinary barriers. This should promote application of clinical reasoning processes to the complex and individual situations that arise in providing a palliative approach to advanced HF care. Such support is necessary for community nurses to be effective advocates for patients and to support families as function declines.[32]

While HF experts have recently promoted the idea that patients with HF should engage in ACP,[7] there are indications that this is not occurring.[17,33] This tool offers nurses a practical guide to integrate ACP issues into the disease-specific issues which patients with advanced HF may face.

A paper-based pocket guide may appear a very traditional mode of KT. However, all participants in this project wanted the simplest method that would be available to them and that was not dependent on electronics. This may be because many nurses practiced in patients' homes in urban and rural communities where technology may be inaccessible. Another issue was that no single electronic technology has been adopted by all nurses or their employers. Printed materials are a relatively inexpensive KT strategy and can be used in most settings. Although pocket guides have been developed for medical management of HF by various specialty groups including the ESC and Canadian Cardiovascular Society, none have specifically integrated a palliative approach to guide EOL care for community-based nurses.

The KTA framework provided a participatory approach to devise a practice tool that would respond to the needs of the nurses. This initiative is an example of both a user pull and exchange effort.[24] One of the strengths of the KTA framework is the emphasis on tailoring new knowledge for different user groups which was central to this project.[34] In the next phase of this KT project, the emphasis will be on moving the HeFPAC into practice. This will require changes in clinician behaviors and work processes. It has been suggested that the KTA framework does not portray the complexities involved in implementing a change in a system.[34] For this reason alternative models will need to be considered for the implementation phase.

Simplification of the tool required that many items that are considered highly significant by HF experts were not included. This was done in response to feedback from nurses to keep the tool simple and consistent with Canadian guidelines. For instance, we did not include the American Heart Association (AHA) stages of HF nor issues related to mechanical support. It is possible the HeFPAC has been over-simplified; this will be an issue for review in future testing. While its current form is designed specifically for use in Ontario Canada, the HeFPAC could be easily modified for broader application in other regions and countries. For instance AHA stages and other web-based resources could be added. Future plans include testing such adaptations in other care contexts and regions. It is planned that the pocket guide will be offered in other modes including the internet and as an 'app'. The HeFPAC will also be piloted in community-based PC practice and integrated into a continuing education program for nurses in Ontario, Canada.

Implications for practice

- The HeFPAC practice tool offers an integrated, evidence-informed, concise, accessible and tangible method for nurses to adopt a palliative approach to the care of patients with advanced HF.
- The HeFPAC has potential to improve HF-related communication with community-based patients with advanced HF, their families and the interdisciplinary care team.
- The HeFPAC could improve disease-specific care provided by PC nurses and others who care for patients with advanced HF outside of HF specialist and PC settings.
- Pilot testing of the HeFPAC will inform future refinements of the tool and its integration into PC and long term care practice settings.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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