

Elizabeth Burden, MD, Susan Anderson, MD, CCFP(PC), MBA, Daisy Dulay, MD, FRCPC

Supportive cardiology: Bridging the gaps in care for late-stage heart failure patients

Interactive tools were created for patients with advanced heart failure and their clinicians to improve information sharing regarding living with the disease, managing symptoms, and making end-of-life decisions.

ABSTRACT

Background: Embedding a palliative approach into management of advanced heart failure remains an important yet challenging aspect of the current care model.

Methods: Late-stage heart failure patients were interviewed about their health care journey, and themes were extracted by multidisciplinary partners. The project team created two original interactive tools for patient and provider perspectives.

Results: The tool for patients and their carers supplements discussions with clinicians regarding prognosis. It focuses on recognizing

signs and symptoms of heart failure progression and exacerbation and outlines skills for adapting to this transition. The aim of the clinician tool is to support clinicians' skills in caring for advanced heart failure patients. It includes guidance through the stages of care and interactive links to further information and support.

Conclusions: Two novel tools were created to address gaps in existing heart failure guidelines and patient education regarding advanced heart failure trajectory that were identified by patients and their providers.

Background

More than one in five Canadians are expected to experience heart failure during their lifetime, and an estimated 600 000 Canadians are currently living with the condition.^{1,2} Through improvements in diagnostics and treatment of cardiac events, heart failure has become a common endpoint for patients with advanced stages of cardiac decline.^{1,3} Heart failure mortality has long exceeded deaths from lung, breast, and prostate cancer combined and has a 1-year mortality rate of 23.4%. Further, up to 80% of heart failure patients will be hospitalized during the last 6 months of life and are more likely than cancer patients to die in the inpatient setting.^{1,4-6} Prognosis aside, the disease course

also brings with it a multitude of symptoms that limit quality of life, including fatigue, dyspnea, angina, anxiety, and depression.⁷

The progressive nature and terminality of heart failure remain poorly appreciated by patients and their caregivers. Ambardekar and colleagues demonstrated discordance between physician and patient perceptions of prognosis and candidacy for invasive measures in advanced heart failure.⁸ The Social Worker–Aided Palliative Care Intervention in High-risk Patients With Heart Failure trial further supported this misperception by showing a frequent overestimation of life expectancy in patients at high risk of heart failure mortality.⁹ The deficit in both end-of-life communication during heart failure and specialist palliative care access has been increasingly recognized over the last decade and beyond. In a 2009 position statement, the European Society of Cardiology addressed the discrepancy in palliative care involvement between heart failure and oncological conditions, despite heart failure being considered equivalent to malignant disease with respect to symptom burden and mortality. Jaarsma and colleagues provided recommendations regarding the timing of a palliative approach, specifically that discussions about goals of care and prognostication should occur early and be revisited frequently.¹⁰

Dr Burden is an internal medicine resident at the University of British Columbia. Dr Anderson is a palliative care consultant, medical director, and division head of palliative and end-of-life care at Island Health and a clinical assistant professor in the Department of Family Practice, UBC. Dr Dulay is a clinical assistant professor in the Department of Cardiology, UBC, a cardiology consultant, and medical director of patient safety and quality at Island Health.

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The integration of a palliative approach into the active management of evidence-based heart failure care remains challenging. As the population ages and the number of patients requiring palliative care increases, specialized palliative care physicians must focus on patients with the most complex biopsychosocial needs due to limited capacity.¹¹ These providers rely on a palliative approach being applied by clinicians of all disciplines to their full scope of practice; for patients with heart failure, that includes the cardiologist and primary care provider. Primary care providers are not always aware of whether their patient is eligible for further disease-modifying cardiac care and, therefore, may expect the cardiologist to convey prognostic information to the patient if this is not possible. However, cardiologists receive little formal training in palliative care, despite frequently encountering such scenarios, and may feel ill-equipped to host discussions about palliation with patients.^{12,13} As a result, the subjects of disease progression and prognosis are often absent in their clinical encounters until a very late stage.¹⁴⁻¹⁶ In terms of feasibility, Gandesbery and colleagues incorporated a palliative medicine service into their heart failure outpatient clinic to achieve an embedded model of care.¹⁷ O'Donnell and colleagues similarly used a palliative approach that involved early conversations on quality of life, prognostic understanding, and end-of-life preferences, which were led by a social worker trained in palliative care; this intervention resulted in both improved documentation of advanced care preferences and patient readjustment of initial baseline prognostic estimates.⁹

Recognizing the challenges for advanced heart failure patients in accessing a palliative approach to care before the final days of life, we explore the gaps in the patient care journey and identify opportunities for improvement. The objective was to create mirrored tools for patients and clinicians that address the same issues but from different perspectives and thereby support improved care and communication for the patient and enhance clinicians' skills. We

outline the needs assessment used and describe the creation and implementation of two interactive tools that were informed by patient experience.

Methods

Patient population

The project was conducted in Victoria, British Columbia. Adults with advanced heart disease (n = 10) were invited by their primary care provider to participate in an hour-long interview about their illness experience. Criteria for recruitment included

Education is paramount in setting expectations of the patient and their carers.

a diagnosis of advanced heart failure with symptoms refractory to maximal medical management and one or more heart failure hospitalizations in the last year. Following national policy and the use of the ARECCI Ethics Screening Tool, this initiative was deemed to be a quality improvement study and was exempt from formal ethical review per Article 2.5 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018).

Initiative

This project was spearheaded by two physician leads: a cardiologist and a family physician with a focused practice in palliative medicine. The objectives were to improve the quality of life and prognostic awareness of late-stage heart failure patients and their carers and increase the comfort and skill of primary care providers in caring for this patient population.

Two novel partnered tools on advanced heart failure were created for clinicians and patients; each is embedded with palliative approaches. The tools were created as original material by the project working group, composed of the physician leads, a heart function clinic nurse clinician, and a cardiology social worker, as well as primary care providers and specialists in cardiology,

palliative care, and internal medicine. The iterative process of tool creation began with a multidisciplinary team meeting in April 2019 to identify a standard clinical pathway for late-stage heart failure patients. Interviews with advanced heart failure patients and their carers were conducted by a cardiology social worker, which provided the group with vital information to identify gaps in the care pathway and determine the most appropriate and relevant content for the tools. Common positive themes included access to and support by primary care providers; challenges identified included inadequate symptom and medication management, system navigation, information sharing, and timing of prognostic conversations. A subgroup was created to include patient partners with lived cardiac experience, who played an integral role in ensuring the patient tool was written in a manner that was applicable to the target audience.

Two plan-do-study-act cycles were completed in January and February 2021 with a focus group of clinicians who reviewed tool content, advised on revisions, and provided recommendations to ensure that the two tools remained complementary.¹⁸ One of the overarching goals of the tool creation was to ensure ease of user experience. To facilitate this, the tools were created through a low-tech platform as interactive PDFs to maximize their use by patients and providers. The content aligns with current recommendations from the most recent practice guidelines from the Canadian Cardiovascular Society, Cardiac Services BC, and BC Centre for Palliative Care.

Results

The tools

The clinician tool, which focuses on delivery of care from the primary care perspective, is divided into three stages of advanced heart failure: (1) transition to late-stage heart failure, (2) periodic assessments and/or exacerbations, and (3) actively dying. Each stage provides guidance on communication, symptom assessment and treatment,

disease modification, and optimization of daily functioning. The platform provides hyperlinked content to respective sections and chapters within the tools and external links to evidence-based resources to supplement the information within the tool. Therefore, the tool provides guidance on issues that arise during the three stages of advanced heart failure and addresses the information needs of multiple clinician groups by providing easy-to-follow prompts and step-by-step descriptions. The aim of the clinician tool is to support clinician skills

in caring for advanced heart failure patients [Figure 1]. The tool is available at <https://pathwaysbc.ca/ci/5231>.

The tool for patients and their carers focuses on recognizing signs and symptoms of heart failure progression and exacerbation and outlines skills to adapt to this transition. It also includes diagrams of disease trajectories, helpful questions to ask, and future conversations to consider. The language provides clear information for the patient, as well as recognition of the carer's role and needs. This tool also

has links to additional resources, which allows the patient to access as much or as little information as they require, at the appropriate time in their health care journey. The overarching purpose of this tool is to foster empowerment and preparation for active participation in discussions and decision-making with the health care team [Figure 2]. The tool is available at <https://pathwaysbc.ca/ci/5230>.

In June 2021, the interactive tools were made available to Vancouver Island users of Pathways, a provincial online resource

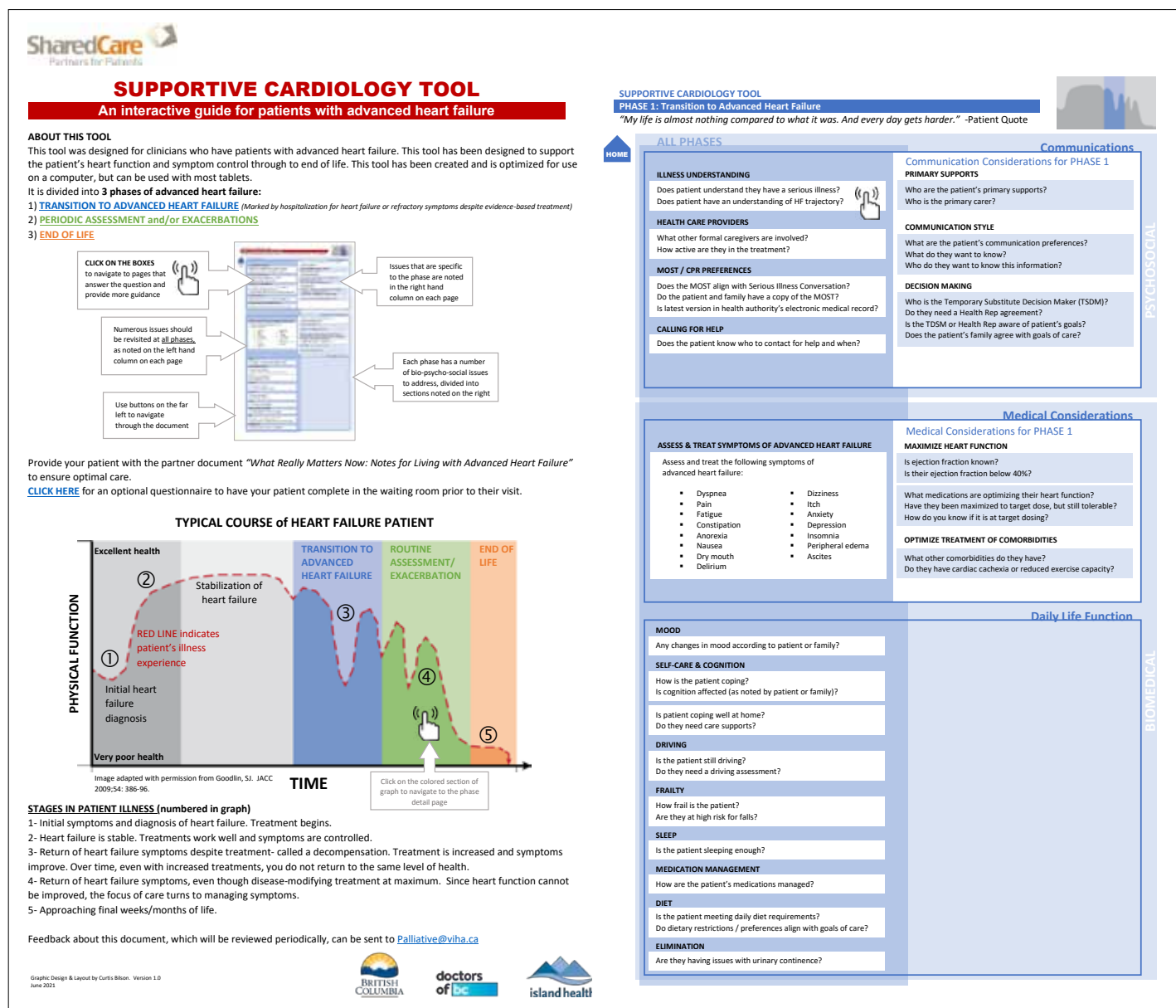


FIGURE 1. Screenshot of the clinician tool (<https://pathwaysbc.ca/ci/5231>).

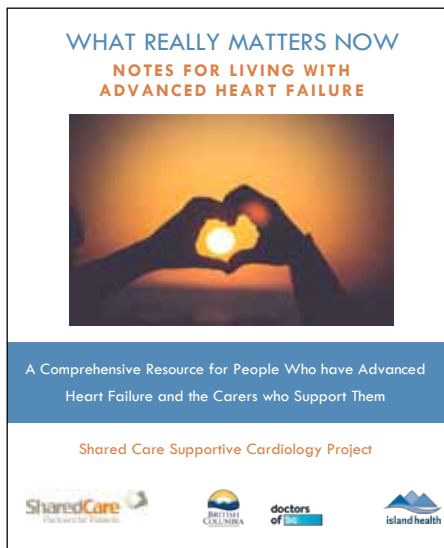


FIGURE 2. Screenshot of the patient tool (<https://pathwaysbc.ca/ci/5230>).

for physicians and their staff supported by the Family Practice Services Committee that provides categorized and searchable patient and physician content. The tools are also available on the Island Health intranet, and work is underway to make them available to Pathways users across the province. The patient tool is currently distributed to patients seen at the heart function clinic in Victoria. Further distribution is being conducted through educational rounds provided to local physician groups. The intention is for the tools to bridge the gaps in existing heart failure guidelines and patient education regarding the disease trajectory [Figure 3].

Discussion

Heart failure is a common, life-limiting illness with an often unpredictable disease trajectory. Its course is unique and challenging and entails navigation of the health care system with multiple care providers. Thus, when a patient is diagnosed with heart failure, education is paramount in setting expectations of the patient and their carers. Similarly, ensuring provider comfort and aptitude in navigating a palliative approach is of utmost importance in promoting effective communication between patient and clinician.

Concurrent administration of supportive palliative care alongside evidence-based disease-modifying therapies is advised in

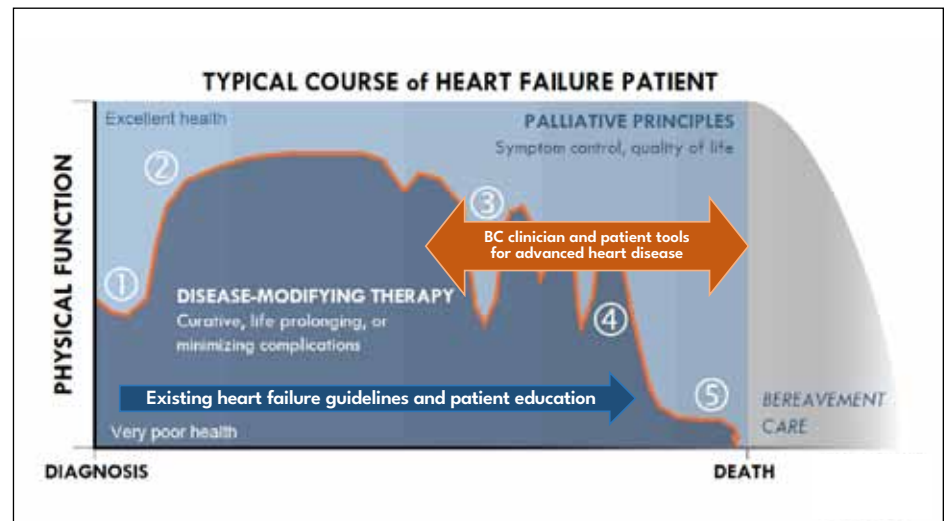


FIGURE 3. Trajectory of heart failure, with a timeline showing where existing guidelines and education extend and where the clinician and patient tools can bridge the gap. Image adapted with permission from Goodlin SJ. *JACC* 2009;54:386-396.

the literature.^{10,19} Nonetheless, it has also been well recognized that palliative care is often missing in the provision of comprehensive patient care in late-stage heart failure.^{10,14-16} Due to the finite availability of palliative care specialists, ill-defined roles among other providers in addressing palliation, and concerns about insufficient training in palliative care, patients with advanced heart failure are frequently not given the information they need to navigate their care and end-of-life decisions.¹¹⁻¹³ This is further supported by our needs assessment of the patient experience: common themes included challenges regarding information sharing with their provider, symptom management, and lack of understanding of their condition. It is essential to highlight the frailty of this patient population: most interviewees did not survive to completion of the project. Mapping the patient journey of those with advanced heart failure has provided improved understanding of their unique experience and the landscape of care for this patient population, as well as a recognition of the importance of primary care providers as a foundational support.

Summary

Two novel interactive educational tools geared toward patient and clinician perspectives on advanced heart failure were

created. They include palliative approaches and considerations that can be incorporated early in the course of caring for these patients. The aim was to better support these audiences by using documented patient experiences and project objectives as guidance. Through the creation of the clinician tool, it is hoped that widespread education about the use of palliative approaches in late-stage heart failure can be achieved in a sustainable, independent manner. Given that the documented patient experiences reiterated the deficit of a palliative approach described in the literature, the patient-focused tool is intended to serve as a supplement to provider communication in managing patient and caregiver understanding of disease state and progression, providing considerations in difficult conversations, and offering available resources.

Study limitations

This work is limited in that patient experiences were obtained from a small, homogeneous population that represented most heart failure patients in our geographic region. We acknowledge that there will be differences in patient preference regarding the tools' level of detail and areas of emphasis. To mitigate this potential barrier, we recommend that these tools be culturally adapted to improve their relevance

to different populations. Ease of use may also be limited because the tools exist in an online, interactive format, which requires technological literacy; therefore, they may not be accessible to the elderly population afflicted with advanced heart failure. The patient tool can be printed, but the length of the clinician tool without the capacity for its interactive, hyperlinked function may preclude use in a paper format. Until adequate time is allowed for providers to incorporate palliative approaches earlier in the disease process, clinical utility of the tool remains to be evaluated.

Next steps

The goal of this project is widespread dissemination of the patient and clinician tools. Further work is ongoing to create connections across the province and beyond to facilitate distribution of the tools on a large scale. The hope is that with increased use, familiarity, and time since implementation, an assessment of clinical utility and patient experience can be completed. ■

Competing interests

None declared. Funding sources had no involvement with the project.

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References

- O'Meara E, Thibodeau-Jarry N, Ducharme A, Rouleau JL. The epidemic of heart failure: A lucid approach to stemming the rising tide. *Can J Cardiol* 2014;30:S442-454.
- Heart and Stroke Foundation of Canada. 2016 report on the health of Canadians: The burden of heart failure. Accessed 18 December 2021. www.heartandstroke.ca/-/media/pdf-files/canada/2017-heart-month/heartandstroke-reporton-health-2016.ashx.
- Johansen H, Strauss B, Arnold JM, et al. On the rise: The current and projected future burden of congestive heart failure hospitalization in Canada. *Can J Cardiol* 2003;19:430-435.
- Adler ED, Goldfinger JZ, Kalman J, et al. Palliative care in the treatment of advanced heart failure. *Circulation* 2009;120:2597-2606.
- Slawnych M. New dimensions in palliative care cardiology. *Can J Cardiol* 2018;34:914-924.
- Unroe KT, Greiner MA, Hernandez AF, et al. Resource use in the last 6 months of life among Medicare beneficiaries with heart failure, 2000–2007. *Arch Intern Med* 2011;171:196-203.
- Nordgren L, Sörensen S. Symptoms experienced in the last six months of life in patients with end-stage heart failure. *Eur J Cardiovasc Nurs* 2003;2:213-217.
- Ambardekar AV, Thibodeau JT, DeVore AD, et al. Discordant perceptions of prognosis and treatment options between physicians and patients with advanced heart failure. *JACC: Heart Fail* 2017;5:663-671.
- O'Donnell AE, Schaefer KG, Stevenson LW, et al. Social Worker–Aided Palliative Care Intervention in High-risk Patients With Heart Failure (SWAP-HF): A pilot randomized clinical trial. *JAMA Cardiol* 2018;3:516-519.
- Jaarsma T, Beattie JM, Ryder M, et al. Palliative care in heart failure: A position statement from

the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. *Eur J Heart Fail* 2009;11:433-443.

- Nowels D, Jones J, Nowels CT, Matlock D. Perspectives of primary care providers toward palliative care for their patients. *J Am Board Fam Med* 2016;29:748-758.
- Hanratty B, Hibbert D, Mair F, et al. Doctors' understanding of palliative care. *Palliat Med* 2006;20:493-497.
- Crousillat DR, Keeley BR, Buss MK, et al. Palliative care education in cardiology. *J Am Coll Cardiol* 2018;71:1391-1394.
- McCarthy M, Lay M, Addington-Hall J. Dying from heart disease. *J R Coll Physicians Lond* 1996;30:325-328.
- Rogers A, Addington-Hall JM, McCoy AS, et al. A qualitative study of chronic heart failure patients' understanding of their symptoms and drug therapy. *Eur J Heart Fail* 2002;4:283-287.
- Boyd KJ, Murray SA, Kendall M, et al. Living with advanced heart failure: A prospective, community based study of patients and their carers. *Eur J Heart Fail* 2004;6:585-591.
- Gandesbery B, Dobbie K, Gorodeski EZ. Outpatient palliative cardiology service embedded within a heart failure clinic: Experiences with an emerging model of care. *Am J Hosp Palliat Care* 2018;35:635-639.
- Langley GL, Moen R, Nolan KM, et al. The improvement guide: A practical approach to enhancing organizational performance. 2nd ed. San Francisco: Jossey-Bass Publishers; 2009.
- Hill L, Prager Geller T, Baruah R, et al. Integration of a palliative approach into heart failure care: A European Society of Cardiology Heart Failure Association position paper. *Eur J Heart Fail* 2020;22:2327-2339.