

# Dying to know: prognosis communication in heart failure

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## Abstract

Prognosis communication in heart failure is often narrowly defined as a discussion of life expectancy, but as clinical guidelines and research suggest, these discussions should provide a broader understanding of the disease, including information about disease trajectory, the experiences of living with heart failure, potential burden on patients and families, and mortality. Furthermore, despite clinical guidelines recommending early discussions, evidence suggests that these discussions occur infrequently or late in the disease trajectory. We review the literature concerning patient, caregiver, and clinician perspectives on discussions of this type, including the frequency, timing, desire for, effects of, and barriers to their occurrence. We propose an alternate view of prognosis communication, in which the patient and family/caregiver are educated about the nature of the disease at the time of diagnosis, and a process of engagement is undertaken so that the patient's full participation in their care is marshalled, and the care team engages the patient in the informed decision making that will guide care throughout the disease trajectory. We also identify and discuss evidence gaps concerning (i) patient preferences and readiness for prognosis information along the trajectory; (ii) best practices for communicating prognosis information; and (iii) effects of prognosis communication on patient's quality of life, mental health, engagement in critical self-care, and clinical outcomes. Research is needed to determine best practices for engaging patients in prognosis communication and for evaluating the effects of this communication on patient engagement and clinical outcomes.

**Keywords** Heart failure; Prognosis; Communication; End of life; Disease progression

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## Introduction

Unlike in other chronic or serious illnesses where the disease trajectory may be linear and more easily predicted, heart failure (HF) is a chronic disease that is characterized by a heterogeneous disease course and multiple co-morbidities.<sup>1,2</sup> Despite advancements in care and more patients living with late phases of the disease, 5-year mortality remains at nearly 53%,<sup>3,4</sup> comparable with that for several cancers.<sup>5,6</sup>

The American Heart Association recommends that discussions focused on quality of life (QoL) and the identification of patient values and goals of care, along with information

about life expectancy, be conducted at annual care reviews for patients with HF.<sup>4,7</sup> Furthermore, the Canadian Cardiovascular Society and the Heart Failure Association of the European Society of Cardiology suggest that discussions about prognosis and related issues occur early in the HF trajectory and following any changes in health status.<sup>8,9</sup> It is important to note however that extant prediction models concerning prognosis in HF are poor.<sup>10,11</sup> Furthermore, as implied in these recommendations, the notion of 'prognosis communication' in HF care may be a misnomer, in that the discussions being recommended by these professional organizations encompass a much broader focus on patient engagement and

an iterative discussion of disease trajectory, as opposed to a conversation narrowly focused on life expectancy estimates. Iterative discussions of this kind could serve as opportunities for better informed decision making and to more fully engage patients in their care—e.g. through better adherence to medication and lifestyle recommendations—and thus potentially alter the disease trajectory.

## Methodology

We review the limited research to identify promising signals and evidence gaps. Additionally, we propose a new model of prognosis communication across the HF trajectory (see *Figure 1*) and discuss research to address these evidence gaps.

For this review, we conducted a search from 1990 to 2017 of PubMed, Scopus, and Cochrane databases. Combinations of terms used include *Communicate, Communication, Prognosis, Prognostic, Future, Expectations, and Disease Severity*. A limited secondary search was conducted in 2018. Additionally, reference lists from published papers were reviewed for potentially relevant articles. Studies were eligible for inclusion if they were published in peer-reviewed journals and available in English (see Table 1 for sample characteristics of studies included in the review).

## Frequency and timing of prognosis communication

Reports on the frequency of prognosis communication include five qualitative studies,<sup>12–16</sup> one mixed-methods study,<sup>17</sup> one observational study,<sup>18</sup> and several self-report survey studies,<sup>19–22</sup> while only three included patients in early HF stages [e.g. New York Heart Association (NYHA) Classes I–II],<sup>12,19,22</sup> a common occurrence in this literature that limits generalization of findings. In these studies, discussions were largely about prognosis and occurred infrequently<sup>13,15,18,20–22</sup> with rates typically ranging from 11% to 38% of patients.<sup>20,22</sup> For example, in one large ( $n = 600$ ) survey that compared caregivers and patients with HF, chronic obstructive lung disease, cirrhosis, and cancer, discussion of prognosis with a clinician was recalled by only 18% of patients with HF and 30% of their caregivers.<sup>21</sup> Similarly, in one qualitative content analysis of 71 audio-recorded clinical encounters, it was found that in only 17 instances did physicians explain the nature of HF, and only once was the life-limiting potential of the disease mentioned.<sup>18</sup> Yet, in one large ( $n = 104$ ) cross-sectional study, between 68% and 90% of patients with HF stated that they had had discussions about what to expect in the future, including prognosis.<sup>19</sup> Interestingly, patients, caregivers, and clinicians appear to differ in their perceptions concerning the occurrence of prognosis communication. In one study of 214 patients with cancer,

**Figure 1** Model of prognosis communication across the heart failure disease trajectory.

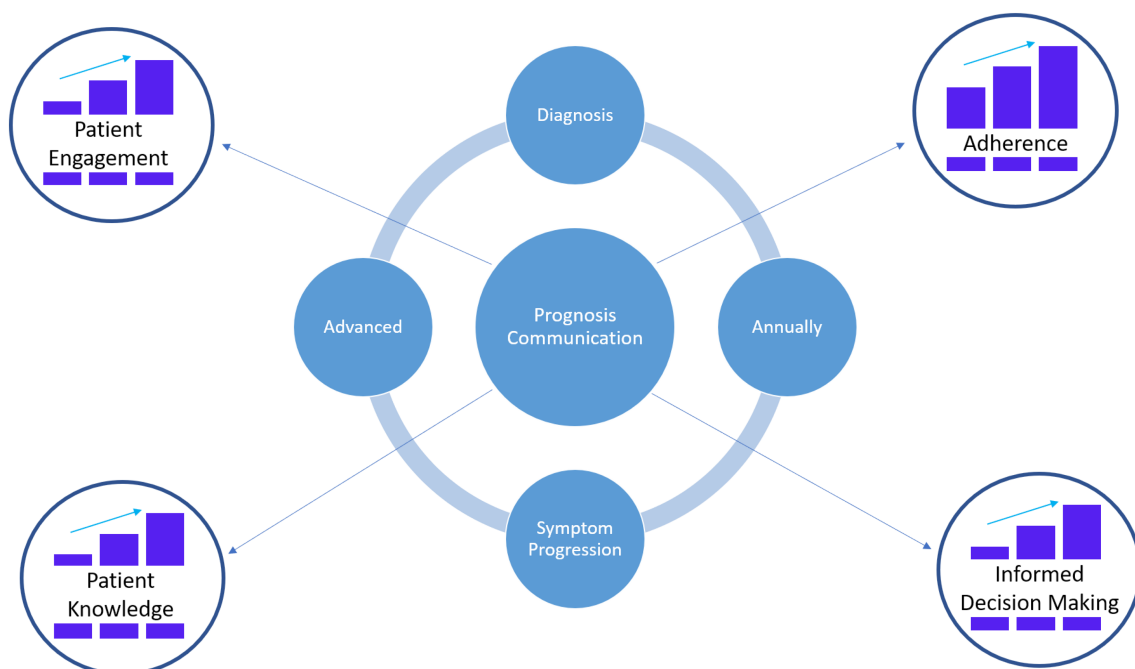


Table 1 Study characteristics

Author	Sample size (N)	Sample characteristics	HF class/stage	Methodology	Key points
Ågård <i>et al.</i> <sup>34</sup>	40	PT	II–IV	QL	1. >75% did not request prognostic information.
Anluwalia <i>et al.</i> <sup>18</sup>	96	PT, CL	93.1% C–D	X <sup>+</sup>	1. In 71 visits, physicians discussed the life-limiting potential of HF one time.
Aldred <i>et al.</i> <sup>12</sup>	20	PT, CA	II–IV	QL	1. Few patients received prognosis information.
Allen <i>et al.</i> <sup>26</sup>	122	PT	I–IV	QT	2. Patients were able to make realistic life expectancy estimates. 1. Median patient predicted life expectancy was 13 years as compared with a median model predicted life expectancy of 10 years.
Barnes <i>et al.</i> <sup>38</sup>	123	PT, CL	III–IV	QL	1. Few patients received prognosis information.
Boyd <i>et al.</i> <sup>39</sup>	20 <sup>a</sup>	PT, CA, CL	IV	QL	1. Patients feared sanctions if they requested additional information from clinicians.
Caldwell <i>et al.</i> <sup>23</sup>	20	PT	85% III	QL	1. Patients preferred learning prognosis information early in the disease trajectory with physicians initiating the discussions and engaging in two-way conversations with patients. 2. Some patients expressed ambivalence about the amount of prognosis information they wanted.
Dougherty <i>et al.</i> <sup>14</sup>	24	PT	C–D	QL	1. Patients expressed that their future was not clearly explained. 2. Patients expressed fear concerning asking clinicians for this information.
Dunlay <i>et al.</i> <sup>24</sup>	95	CL	N/A	QT	3. Patients expressed that specific life expectancy estimates were not helpful. 1. 12% of clinicians have end-of-life discussions annually. 2. 52% of clinicians were hesitant to have these discussions due to discomfort, perception that patient or family lacked readiness, fear of causing a loss of hope, and lack of time. 3. 30% of clinicians described a low or very low level of confidence in initiating prognosis discussions.
Fried <i>et al.</i> <sup>17</sup>	503 <sup>b</sup>	PT, CA, CL	+	QT	1. 55% of patients with HF wanted to know their life expectancy. 2. 20% of patient–clinician and 21% of caregiver–clinician pairs agreed that the fatal nature of their illness had been discussed. 3. 3% of patient–clinician and 7% of caregiver–clinician pairs agreed that they discussed life expectancy. 4. 46% of clinicians (in patient–clinician pairs) reported that the fatal nature of the illness had been discussed, and 23% of clinicians reported that life expectancy had been discussed.
Gerlich <i>et al.</i> <sup>15</sup>	12	PT	+	QL	1. Patients and caregivers rarely discussed prognosis.
Gordon <i>et al.</i> <sup>19</sup>	104	PT	II–III	QT	1. 68% of patients had discussed prognosis. 2. 80.6% of patients who had not discussed prognosis expressed a desire for this information.
Gott <i>et al.</i> <sup>13</sup>	40	PT	III–IV	QL	1. Few patients engaging in prognosis discussions. 2. Some patients stated that they did not want prognosis information.
Hanratty <i>et al.</i> <sup>43</sup>	34	CL	N/A	QL	1. Clinicians expressed concern about discussing prognosis too soon and having the patient lose faith in the team. 2. Clinicians described themselves as poor at prognostication in HF.
Hanratty <i>et al.</i> <sup>40</sup>	50 <sup>b</sup>	PT	+	QL	1. A majority of patients were not informed about their prognosis.

(Continues)

Table 1 (continued)

Author	Sample size (N)	Sample characteristics	HF class/stage	Methodology	Key points
Harding <i>et al.</i> <sup>41</sup>	43	PT, CA, CL	III–IV	QL	<p>2. Patients reported that they were unlikely to seek information because they feared being perceived as bothersome.</p> <p>1. Clinicians attributed non-adherence to patients' lack of understanding.</p> <p>2. No patients and caregivers received prognosis information.</p> <p>3. Clinicians identified the unpredictable trajectory of HF, cognitive impairments, and lack of time and resources as barriers to prognosis communication.</p> <p>1. 18% of patients and 30.1% of family members reported having prognosis discussions with clinicians.</p> <p>2. Patients who recalled these discussions reported more satisfaction with care.</p>
Heyland <i>et al.</i> <sup>21</sup>	600 <sup>b</sup>	PT, CA	IV or EF ≤ 25%	QT	<p>1. 96% of HF nurses reported discussing prognosis with patients.</p> <p>2. 69% of HF nurses reported that clinicians should be primarily responsible for prognosis discussions.</p> <p>3. HF nurses identified the following as barriers to these conversations: the unpredictable trajectory of HF, patient co-morbidities, cognitive impairments, worrying about causing a loss of hope, and lack of time.</p> <p>4. 18% identified a lack of communication skills as a barrier.</p> <p>1. 38% of patients received prognosis communication.</p> <p>1. Patient views concerning desire for prognosis information were mixed.</p> <p>1. 44% of patients wanted more prognosis communication.</p> <p>2. Patient desire for more prognosis communication was associated with higher self-efficacy scores and increased odds of hospitalizations.</p> <p>1. Patients often did not perceive the life-limiting aspect of HF and had little knowledge about prognosis.</p> <p>2. Patients attributed HF to old age.</p> <p>1. Patients with HF had a poorer understanding of their prognosis than patients with cancer.</p> <p>2. Patients with HF received fewer services than patients with cancer.</p>
Hjelmfors <i>et al.</i> <sup>44</sup>	111	CL	N/A	QT	<p>1. 17 patients expressed a desire to receive their SHFM estimates.</p> <p>2. Patients who received their Seattle Heart Failure Mode (SHFM) estimates described experiencing control and hope.</p> <p>1. Patients in a palliative care intervention were more likely to report prognoses aligned with clinician assessment.</p> <p>2. Patients in the intervention group did not experience significant changes in depression, anxiety, or quality of life (QoL).</p> <p>1. Patients with HF were unsure of the course of HF in the future.</p> <p>1. Patients who discussed prognosis with a clinician also described a more uncertain future.</p> <p>2. Patients who had not discussed prognosis expressed interest in receiving prognosis information.</p> <p>1. Some patients lacked knowledge about their prognosis.</p>
Hjelmfors <i>et al.</i> <sup>22</sup> Horne and Payne <sup>35</sup>	279 20	PT, CL PT	I–IV II–IV	Mixed QL	
Howie-Esquivel and Dracup <sup>36</sup>	47	PT	II–IV	Mixed	
Klindtworth <i>et al.</i> <sup>27</sup>	25	PT	III–IV	QL	
Murray <i>et al.</i> <sup>16</sup>	40 <sup>a,b</sup>	PT, CA, CL	IV	QL	
Narayan <i>et al.</i> <sup>33</sup>	24	PT	II–IV	QL	
O'Donnell <i>et al.</i> <sup>37</sup>	50	PT	64% III–IV	QL	
O'Leary <i>et al.</i> <sup>32</sup> Rodriguez <i>et al.</i> <sup>31</sup>	100 <sup>b</sup> 25	PT PT	III–IV 52% II	Mixed QL	
Rogers <i>et al.</i> <sup>29</sup>	27	PT	II–IV	QL	

(Continues)

Table 1 (continued)

Author	Sample size (N)	Sample characteristics	HF class/stage	Methodology	Key points
Selman <i>et al.</i> <sup>42</sup>	43	PT, CA, CL	III–IV	QL	2. Some patients may have been aware of their prognosis but did not acknowledge it. 1. Clinicians reported that it was difficult to discuss poor prognosis. 2. Clinicians identified a lack of communication skills as a barrier to prognosis communication.
Strachan <i>et al.</i> <sup>20</sup>	106	PT	IV or EF < 25%	QT	1. 11.3% of patients had discussed life expectancy with their clinician.
van der Wal <i>et al.</i> <sup>25</sup>	678	PT	II–IV	QT	1. 2.1% of patients were unsure of future expectations concerning HF. 2. 13% of patients expected to be cured. 3. Deterioration expectations were associated with lower QoL score, greater worry about the future, more dissatisfaction with care, higher mortality rate, and more HF readmissions.
Willems <i>et al.</i> <sup>28</sup>	31	PT	III–IV, or EF < 25%, or at least one hospitalization due to HF	QL	1. Most patients were unaware that they may die earlier because of HF.
Zapka <i>et al.</i> <sup>30</sup>	90 <sup>b</sup>	PT	+	Mixed	1. Patients with HF were less aware of their prognosis as compared with patients with cancer.

CA, caregiver sample; CL, clinician sample; EF, ejection fraction; QL, qualitative methodology; QT, quantitative methodology; Mixed, mixed-methods; N/A, NYHA class or ACC/AHA stage not applicable due to sample including only clinicians; Not reported, total sample size not reported; PT, patient sample; X+ qualitative analysis of observational data; +, NYHA class or ACC/AHA stage not reported, but samples described as having a limited life expectancy, advanced HF, or being in the last year of life.

<sup>a</sup> Number of patients included in study, but an unknown number of caregivers and/or clinicians were also included.

<sup>b</sup> Sample included patients with other chronic illnesses (e.g. cancer and chronic obstructive pulmonary disease).

HF, or chronic obstructive pulmonary disease and limited life expectancy, only 20% of patient–clinician and 21% of caregiver–clinician pairs agreed that the fatal nature of the illness had been discussed, and only 3% of patient–clinician and 7% of caregiver–clinician pairs agreed that discussion about life expectancy had occurred.<sup>17</sup> Yet 46% of clinicians (in patient–clinician pairs) reported discussing the fatal nature of the illness with the patient, and 23% reported discussing life expectancy, with similar findings for caregiver–clinician pairs.

This apparent ‘disconnect’ can easily occur at the end stage of a disease such as HF, when the issues at hand are fraught with concerns about impending mortality. Indeed, a small ( $n = 20$ ) study of patients with HF found that some expressed a preference to receive prognosis information close to the time of HF diagnosis, when they are more likely to be alert, while others expressed a preference for having multiple opportunities to discuss prognosis—e.g. so that they had multiple opportunities to absorb the information.<sup>23</sup> Yet, in one study of HF clinicians ( $n = 95$ ),<sup>24</sup> only 12% reported having annual focused discussions with patients, and these were limited to end-of-life discussions, while in another study ( $n = 279$ ), from Sweden and the Netherlands,<sup>22</sup> clinicians indicated that prognosis discussions occur most often when a patient experiences a decline in health status or when they are approaching end of life. These clinicians also noted that there was no agreement on the correct timing for these discussions with patients.<sup>22</sup> Thus, there is little data to inform timing of prognosis information from the patient perspective, and the two studies of clinician preference demonstrate deviation from recommendations.

## Patient understanding of prognosis communication

The infrequent occurrence of prognosis communication may be a contributing factor to patients’ limited understanding of the nature and trajectory of HF. One large study of patients ( $n = 678$ ) found that 25% had little knowledge about future health expectations and 13% expected to be cured.<sup>25</sup> In addition, in a prospective survey ( $n = 122$ ), patients with HF estimated their life expectancy as a median of 13 years as compared with model predictions of a median of 10 years.<sup>26</sup> Furthermore, although 51% of patients expected to have HF for the rest of their lives, they did not expect the disease to reduce their lifespan.<sup>26</sup> Several other studies have also shown that patients with HF do not appreciate the terminal nature of their disease even when compared with other chronic or terminal illnesses.<sup>15,16,27–30</sup> For example, two studies suggest that patients with HF are less aware of their prognosis as compared with patients with advanced cancer<sup>30</sup> and that patients with advanced HF do not acknowledge the terminal nature of HF, whereas those with lung cancer appear to

understand their disease status.<sup>16</sup> Overall, these studies suggest that a lack of prognosis communication may contribute to patients with HF having a limited understanding of prognosis. Also of note, two small qualitative studies ( $n = 25$ <sup>31</sup> and  $n = 27$ <sup>29</sup>) suggest that patient understanding of prognosis can be limited even when clinicians have discussed this with them<sup>31</sup> or that while aware of prognosis, they are reluctant to acknowledge it.<sup>29</sup>

Yet other research suggests that patients may understand the poor prognosis associated with HF even in the absence of prognosis communication. A small, qualitative study of 10 patients with NYHA Class II–IV HF found that many are aware that their prognosis is poor even when they have not discussed this with their clinician.<sup>12</sup> Similarly, one mixed-methods study of 50 patients with cancer and 50 patients with HF found that patients may recognize the incurable nature of HF even when they lack an understanding of disease trajectory.<sup>32</sup> These findings suggest that prognosis communication involves a complex discussion, which may be difficult for patients to fully understand, especially if it occurs infrequently throughout the disease trajectory.

## Patient desire for prognosis communication

Although largely limited to samples consisting of patients in early stages to mid-stages of HF, research primarily shows that patients want prognosis discussions to occur, despite some variability in patient and caregiver desire for discussions about prognosis, both within and across studies.<sup>17,19,33–35</sup> One small, qualitative study ( $n = 25$ ) showed that most patients desired information about their disease,<sup>31</sup> while a cross-sectional study with a relatively large sample ( $n = 104$ ) found that over 87% wanted to discuss what to expect in the future concerning HF and over 80% wanted to specifically discuss their prognosis.<sup>19</sup> Although a smaller study ( $n = 24$ ), other research has similarly shown that over 70% of patients elected to receive their individualized survival estimates even when informed that available models do not provide clear prediction.<sup>33</sup> Yet other studies show more variability within samples.<sup>17,35,36</sup> One study of 47 hospitalized patients with HF reported that almost half wanted more discussion about prognosis, while more than half wanted information regarding disease self-management.<sup>36</sup> Similarly, in one small qualitative study ( $n = 20$ ), some patients expressed a desire for prognosis information, while others preferred not to discuss prognosis.<sup>35</sup> In another cross-sectional study, 55% of patients with HF and 75% of their caregivers wanted information concerning life expectancy.<sup>17</sup> Understanding patient preferences is further complicated by one qualitative study ( $n = 20$ ) showing that even when patients express a preference for receiving

prognosis information, they can express ambivalence about how much information they want.<sup>23</sup> Furthermore, a qualitative study of 40 patients reported that most preferred to have only a vague understanding of their prognosis, with fewer than 25% specifically asking for prognosis information.<sup>34</sup> These findings provide a window on the individual nature of the HF patient experience.

## Benefits and consequences associated with discussions about prognosis

While observational, several studies suggest that there can be important benefits associated with prognosis communication. For example, in a large survey ( $n = 600$ ), patients who recalled having a prognosis discussion with a clinician endorsed higher satisfaction with decision making, end-of-life care, and with communication vs. those who did not recall having these discussions.<sup>21</sup> Additionally, in a small, qualitative study of patients with NYHA Class II–IV HF ( $n = 24$ ), those who elected to receive life expectancy estimates reported greater clarity and a sense of control and hope, regardless of whether the information received was positive or negative, though in this study, no data were reported for patients who declined this information.<sup>33</sup> Furthermore, in a pilot randomized trial of a palliative care intervention for high-risk patients with HF ( $n = 50$ ), those randomized to receive the intervention were more likely to have revised their own prognosis assessment to align with that of their physician, with no adverse effects as reflected by depression, anxiety, or QoL.<sup>37</sup> Overall, these findings suggest that discussions about prognosis specifically can promote a better understanding of HF and facilitate informed decision making and future planning, without compromising QoL.

In contrast, other studies have shown an association between awareness of prognosis or desire for prognosis information and consequences. For example, one small study of hospitalized patients with HF ( $n = 47$ ) found that those who wanted more discussion about prognosis were more likely to be rehospitalized,<sup>36</sup> while in a larger study ( $n = 678$ ), patients who expected a deterioration in their health had a lower QoL, were more worried about future health and more unsatisfied, and had more HF readmissions, more days hospitalized due to HF, and a higher mortality,<sup>25</sup> though the expectation of decline and the poorer outcomes may both have been reflective of patients being highly compromised by their disease. Although these studies may suggest that prognosis communication is associated with consequences, it is important to note that prognosis communication was not delivered as part of either study.

## Barriers to prognosis communication

Research concerning barriers to prognosis communication includes eight qualitative studies with mostly small samples,<sup>14,23,38–43</sup> thereby limiting generalization of findings. Despite these limitations, clear themes in patient barriers emerge. Patients with HF who desire prognosis information are unlikely to independently seek it, due in part to fears about what they might learn concerning their future health (according to one small qualitative study,  $n = 24$ )<sup>14</sup> but more importantly because of fear that asking for this information might affect their care.<sup>39</sup> In two small qualitative studies, some patients expressed worry about being perceived as bothersome to clinicians<sup>40</sup> or feeling as though their request for information would make their clinician uncomfortable.<sup>23</sup> One qualitative study found that some patients even feel that clinicians may enforce sanctions against them if patients are viewed as difficult.<sup>39</sup> Similarly, in another small qualitative study ( $n = 43$ ),<sup>41</sup> caregivers and patients described a lack of power in their relationship with clinicians, which reduced their comfort for initiating discussions about prognosis, thereby leaving these conversations for clinicians to initiate.

Clinicians have identified a range of barriers related to both patient characteristics and the nature of HF. For example, one small qualitative study ( $n = 43$ )<sup>41</sup> found that clinicians were concerned that cognitive or other sensory impairments could limit a patient's ability to understand the information presented. Additionally, evidence from a large national survey ( $n = 111$ )<sup>44</sup> showed that clinicians also expressed concern that prognosis discussions could lead to hopelessness and broader negative effects on patients who specifically may be reluctant to receive any prognosis-related information. Similarly, clinicians in a large qualitative study ( $n = 123$ )<sup>38</sup> expressed concern that these discussions could cause alarm, depression, and anxiety among patients with HF. Furthermore, clinicians have also described a reluctance to discuss prognosis in cases in which a patient has multiple comorbidities, and there is a perception that another illness may contribute to the patient's death.<sup>44</sup> Many clinicians are also unclear if prognosis information has previously been communicated, given the number of providers typically involved in HF care.<sup>41</sup> Some describe a lack of time and resources needed to effectively engage in these conversations,<sup>41,44</sup> while still others describe a lack of confidence,<sup>24</sup> believing they do not have sufficient skills to engage patients and their caregivers in prognosis discussions.<sup>39,42,44</sup> This hesitancy is further complicated by the non-linear nature of the HF disease trajectory<sup>38,41,44</sup> and the limitations of current predictive models.<sup>10,11</sup>

One important barrier concerns the imprecision of predictive models in HF, which results in poor to modest prognostication.<sup>11</sup> A prior systematic review concluded that

many prediction models were only moderately successful at predicting mortality.<sup>10</sup> Despite these concerns, HF clinicians acknowledge the value of discussions concerning prognosis.

## Summary

Of the reviewed studies, the great majority were small and qualitative in nature or used mixed methods, with only one—pilot—randomized, controlled trial. Yet a general lack of communication concerning prognosis and related issues is apparent. Both patient and clinician barriers to this communication are evident and are primarily related to patient reluctance to ask for this information<sup>14,23,39–41</sup> and clinician ambivalence to engage patients in these discussions, in part, because of limitations in predictive models<sup>11</sup> and the inherent unpredictable disease trajectory of HF.<sup>45</sup> Clinicians also feel unprepared to engage patients<sup>24,38,39,42,44</sup> and are worried about negative consequences, including the potential impact on patients' QoL.<sup>39,43,44</sup> For example, clinicians express concern that patients may become hopeless or depressed if they receive information concerning their prognosis.<sup>38,44</sup> Less clear is how to engage patients in prognosis discussions, how to adapt these discussions according to each patient's information preferences, the timing for delivering of this information, and how best to assess the effects of these discussions on the patient. Several key knowledge gaps in HF care emerge. These include (i) how to determine patient readiness and preferences for prognosis information as they progress along the disease trajectory; (ii) what are the best practices for communicating prognosis information; and (iii) what are the effects of prognosis communication on patient QoL, mental health, engagement in critical self-care, and outcomes.

## Discussion

Given the poor discrimination of many prognostic models and the inherent unpredictable disease trajectory of HF, uncertainty in prognostication persists.<sup>46</sup> Although this uncertainty is difficult for patients, caregivers, and clinicians to accept,<sup>47,48</sup> experts argue that research on communication concerning prognostic uncertainty is just as important as the development of better prognostic models<sup>48</sup> as prognosis communication will allow patients to more fully engage in their care and in decision making.<sup>49</sup> In *Figure 1*, we propose a model of prognosis communication across the HF disease trajectory. This model emphasizes the importance of prognosis communication occurring at critical milestones in a patient's trajectory, including at the time of diagnosis, annually, during episodes of symptom progression (e.g. hospitalization, change from NYHA Class II to III, device

implantation or replacement, adjustments to guideline-directed medical therapy, or device management), and when HF has entered an advanced stage. Although some clinical milestones, such as prior to device implantation or replacement, have long been recognized as necessitating discussion about prognosis,<sup>4</sup> other milestones, such as adjustments to guideline-directed medical therapy, are more subtle and as a result have often been overlooked.<sup>4</sup> Yet these more subtle milestones must be recognized as critical opportunities to engage patients in their care and thus as opportunities to increase patient knowledge, adherence, and informed decision making. Engaging patients in these iterative conversations is necessary to address the barriers identified by clinicians, including the potential for cognitive impairments to limit patients' ability to understand this information. Furthermore, these conversations provide an opportunity for clinicians to discuss goals of care with patients, such as the potential for disease modification. Given the HF disease trajectory, improvement may not always be a reasonable or attainable goal, despite cardiology's focus on disease improvement. Rather, clinicians may want to consider the importance of disease modification as a motivating factor for engaging patients in their care as their ability to promote disease modification is at least partially under their control and related to adherence to medications as well as to dietary and physical activity recommendations.

Patient-centric communication guides, such as the 'Ask-Tell-Ask' model<sup>50</sup> and the 'Serious Illness Conversation Guide',<sup>51</sup> may provide a structure for clinicians to engage patients in prognosis communication.

These guides allow clinicians to acknowledge and normalize the uncertainty associated with prognosis discussions in HF care while helping the patient and caregiver manage the uncertainty.<sup>48</sup> The guides also provide recommended communication strategies for an individualized approach to the delivery of health information with a goal of promoting patient engagement in their own care. An essential ingredient in these communication guides is an assessment of patient readiness to receive health information at each clinical encounter, along with an assessment of patient preferences for the types of health information they wish to receive at the encounter.<sup>50,51</sup> This encourages the patient to ask questions and discuss care preferences, without having the discussion move beyond what the patient wants or is ready for. It also allows for change over time, as what the patient wants and is ready to discuss changes with the progression of the disease—e.g. as symptom management becomes more difficult and life limiting.<sup>52</sup> *Figure 2* provides an overview of prognosis communication at several different points along the disease trajectory, using principles of the 'Ask-Tell-Ask' model and related communication strategies.

While these patient-centred guides provide a framework that holds promise for realizing regular and effective



**Figure 2** Prognosis communication in heart failure across the disease trajectory.

Skill	Stage	Communication Example
Ask		"Tell me what you know about your heart condition."
Assess		"How much information do you want about your heart condition? Do you want to understand how it affects your health, impacts your survival, and what you can do to help?"
Tell	Diagnosis	"It's difficult to estimate a patient's individualized life expectancy at this stage of heart failure. We also know that some of our models are unfortunately not very accurate. What we do know is that heart failure is a serious, chronic illness that can eventually lead to death. We also know that your engagement in your care is critical. Let's talk a little bit more about how heart failure will affect your health and quality of life and what you can do to help manage your heart failure."
	Annual	"Heart failure is a chronic illness and although there may be times when you feel better, your heart cannot return to its' original health. As we discussed it's difficult to estimate a patient's life expectancy, but we know that about 50% of people with heart failure survive 5-years after diagnosis. If you are interested in more specific information about your individualized life expectancy estimates we can discuss this, but it's important to remember that this information may not be very accurate. I also think it's important to talk about your follow-through with our treatment plan, and how this affects your future health."
	Symptom Progression	"Any time a patient's health declines, it is important to look at their individualized survival estimates. Let's review this information and discuss what it means for you moving forward and what you might be able to do to help your future health. Can we discuss this information?"
	Advanced	"At this time it appears that your heart failure is considered advanced, in what we classify as class III, which means that it's difficult for you to engage in physical activity and that activities may cause you to feel fatigued or short of breath. It might be helpful for us to review your individualized survival estimates again so we better understand your life expectancy, what to expect, and what we can do to help."
Ask		"This is a lot of information and can be difficult to understand. Tell me your understanding of how heart failure affects your future. I also want to make sure I address any questions or concerns you have. What are your questions or concerns?"
Empathize		"I understand this is difficult information; it can be upsetting."
Plan		"We will continue to work together to treat your heart failure and help you reach your goals."

prognosis communication in HF care, the testing of their utilization in clinical trials remains to be realized. The nature of HF care provides a number of obstacles to testing implementation, some of which are based in structural elements of care delivery. Cluster randomization provides one approach to meeting these structural obstacles, leveraging the expansion of healthcare systems composed of multiple hospital and outpatient settings, and the use of quality improvement efforts that test implementation of new care pathways holds promise. Additionally, given the uneven and unpredictable disease trajectory, outcomes in trials that test these guides should perhaps focus initially on whether the communication with the patient is 'working'—e.g. whether there is consensus between patient and clinician that communication occurred, whether the patient and their caregiver can demonstrate understanding of the communication, and whether the receipt of this communication affects overall adherence, QoL, and satisfaction with care. Additionally, it will be important to test different delivery models—e.g. training of HF staff in a given clinic/hospital setting vs. incorporation of a prognosis communication specialist on the care team. Future research examining prognosis communication will need to address these gaps in the literature.

Furthermore, training of clinicians in patient-centred communication should be prioritized. Incorporating training in this type of patient-centred communication for clinicians in

medical school and residency as well as requiring continuing medical education in this style of communication would potentially increase the likelihood that clinicians are prepared to engage patients in these types of conversations. Critically, this type of training will need to include interactive components, such as through simulated patients and role-playing exercises. Training utilizing these methods will better prepare clinicians to engage in patient-centred communication throughout the HF disease trajectory. Future research will need to examine optimal training methods in patient-centred communication with a focus on addressing the barriers identified by both patients and clinicians. It will also be important for future research to consider clinicians' training pathways and cultural differences when designing and implementing training in patient-centred and prognosis communication.

Critically, promoting uptake of prognosis communication will require a shift in the HF model of care, such as a team-based care programme. Given that HF care, unlike cancer, typically involves a number of clinicians who often operate in silos, HF clinicians often feel unsure if prognosis communication has occurred previously<sup>41</sup> and are hesitant to engage patients in these conversations due to concern about patients' emotional responses to this information.<sup>39,43,44</sup> Implementing a team-based care programme would ensure consistency in care and communication, which may help to mitigate any potential negative

patient responses and help to identify a primary clinician responsible for engaging patients in these conversations. Furthermore, previous research has shown the effectiveness of team-based care in reducing hospitalizations and improving functional status as well as QoL.<sup>53</sup> Yet research is needed to examine how prognosis communication can be incorporated into team-based care programmes and to examine the effects of this communication within these programmes.

## Conclusions

While preliminary, research indicates that most patients with HF and their caregivers desire information regarding prognosis and disease trajectory. Yet there are multiple barriers and concerns to conveying this information, and best practices are limited. Moreover, the effects of this information on relevant patient and clinical outcomes are not well studied. Future research will need to investigate how best to engage patients with HF in prognosis communication along the disease trajectory.

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## Author contributions

C.E.C. and M.M.B. contributed to the design conception and drafted the manuscript. All authors performed major revisions to the manuscript.

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