

The complexity of prognosis communication in heart failure: Patient and cardiologists' preferences in the outpatient clinical setting

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ABSTRACT

Background: The determination of prognosis in heart failure (HF) has focused primarily on the identification of potential biological and physiological markers and not on communication. High morbidity and mortality rates suggest that patients require prognostic information to assist in life planning. This study examined the preferences of both patients with HF and cardiologists for prognosis communication in the outpatient clinical setting, with the aim of guiding practitioners in undertaking prognosis conversations. **Methods:** Using qualitative descriptive techniques informed by a grounded theory approach, 32 patients with HF and 9 cardiologists from outpatient settings in Ontario, Canada were interviewed to identify convergent preferences for prognosis communication. Strategies to enhance methodological rigor were employed. **Results:** Individualized, context-specific prognosis communication between patients and cardiologists was preferred. Two main themes and ten related attributes were identified to describe convergent preferences: 1) Set the Stage for Prognosis Communication, and 2) Map the HF route. Attributes reflected the complex, dynamic, interactive and iterative nature of prognosis communication preferences. **Conclusions:** Prognosis communication occurs within a complex, adaptive healthcare system. While specific preferences exist, changing contextual elements within and outside of the system create conditions that require cardiologists to adjust their approach to individual patients. Patients with HF and cardiologists each have preferences that affect their willingness and ability to engage in dyadic HF-specific prognosis communication. Findings have relevance for the implementation of any efforts, including HF guidelines, aimed at improving prognosis communication. Our

findings, informed by a complexity science approach, offer an innovative and robust alternative to traditional linear approaches to prognosis communication.

Keywords: Heart Failure; Prognosis; Communication; Complex Adaptive Systems

1. INTRODUCTION

Improvements in medical management and coronary interventions for those suffering from heart failure (HF) have resulted in a paradox in which increased survival has shifted the focus away from the associated very high morbidity and mortality. Despite these improvements, HF is associated with annual mortality rates of 5% to 50% [1-4]. Patients living with HF typically experience either a sudden death or a prolonged period of decline characterized by recurrent HF-related hospitalizations and worsening symptoms that precede death [3,5]. The uncertainty associated with these trajectories has contributed to HF being viewed as a condition with an unpredictable course and indeterminate prognosis [6]. In the face of this, a growing body of empirical evidence underscores the need for prognosis communication as part of a comprehensive approach to advance care planning and end-of-life care for patients with HF [7-9]. Outpatients with advanced HF indicated that inadequate prognosis communication with physicians left them excluded from supports that could ease their suffering [10]. Hospitalized patients have expressed inconsistencies about whether they wanted to know their prognosis, leaving questions for physicians about how to best communicate about end of life planning and care [8,11].

Patients' preferences for information and treatment are critical for the delivery of ethical, patient-centered, efficient care [12]. Moreover, the influence of physician

preferences in this regard is often based on flawed assumptions about what patients want [12]. If one assumes that prognosis communication is a process involving two or more interacting participants, and is not a unilateral information dump, there is a need to understand the nature of patient and physician preferences and how they relate to one another.

Guidelines in North America and Europe encourage prognosis communication early after diagnosis and during the illness course [6,3,14]. Clearly, the preferences of physicians about the disclosure of prognostic information has an impact upon the content and process by which patients with HF learn about prognosis, yet this has remained relatively unexplored [15]. Instead, literature about prognosis in HF has been dominated by a search to identify prognostic indicators. The assumption that prognosis cannot be predicted until a reliable indicator is found promotes uncertainty about undertaking any associated communication that could be seen to unduly alarm patients. While this may make sense to some providers, such a traditional linear approach is ill-suited to the real world in which HF care is provided. Waiting for clear indicators before initiating conversations is adopting a “binary” (all-or-none) approach to a situation which cries out for flexibility and adaptability in response to individual patients.

A previous study was undertaken to develop an approach to interviewing patients with HF about preferences for prognosis communication [16]. Patients said they wanted to learn about their prognosis when newly diagnosed, when they felt mentally able to engage in informed decision making, and that they wanted control over the timing of prognosis discussions. They wanted physicians to be truthful about prognostic possibilities and to stay hopeful about the outcome. This paper, based on a separately funded study, extends that work and triangulates cardiologists’ and patients’ preferences for prognosis communication, with the goal of developing concepts common to both groups on which a future practice model for prognosis communication can be based. As the study progressed the authors were able to identify patterns and relationships which emerged from participants in the real world, outpatient setting. It became clear that many of the precepts of complexity science, as reflected in complex adaptive system (CAS) principles, were suited to promoting an understanding of both patient and physician preferences in prognosis communication. Several authors were particularly helpful in this regard [17-19], clarifying the concept that cardiologists and patients are participants or “agents” interacting within the HF-related care system. The data gathered during this study provided multiple examples of the properties and characteristics of CAS as experienced by patients

and providers.

2. METHODS

A qualitative descriptive approach informed by grounded theory techniques [20] was employed to uncover major concepts central to prognosis communication and that would reflect a convergence of patients’ and cardiologists’ preferences. Ethics approval was obtained from the university associated with the study. Outpatients at a Heart Function Clinic (HFC) in Ontario, Canada who met the following criteria were eligible for the study: confirmed diagnosis of HF, New York Heart Association (NYHA) Functional Class III-IV over the past 6 months; no documented cognitive impairment in the patient’s chart; able to speak English, provided written informed consent and agreed to an individual, taped interview. We recruited cardiologists who practiced in a variety of outpatient HF settings. Cardiologists in southern Ontario, associated with the Canadian HF Clinic Network, were invited by letter to participate. Inclusion criteria were: English-speaking; involved in the care of patients with advanced HF, and agreed to one-to-one audio-taped interview. Interviews were held at a time and place convenient to participants. An audit trail was maintained to document the research process, including recruitment, interview questions and coding decisions.

Patient interviews were completed by two interviewers; (PS), a Doctorally prepared nurse with expertise in interviewing and qualitative methods, and a Master’s prepared research assistant with expertise in conducting clinical research with cardiac populations. PS completed all interviews with cardiologists. To ensure consistency, the interviewers met regularly to review the transcripts and make adjustments to the interview guide as needed (e.g., for clarification or to probe emerging concepts). A semi-structured interview format was adopted. Patient interviews began with a question about how important they thought it was for them to understand how HF may affect them in the future. Cardiologists were asked about how they preferred to approach prognosis communication. Follow-up questions for both groups included how preferences for content, timing and approach to learning about prognosis changed over the course of HF, as well as what made those conversations easier or difficult. They were asked to provide examples of situations to illustrate those preferences.

Interviews were transcribed verbatim and conventional data analysis procedures common to grounded theory were utilized [21]. Two analysts (PS and EG) coded the transcripts independently using line by line analysis, open and axial coding and constant comparison in which emerging thematic concepts were challenged against new data. Analysts met regularly to compare coding and

reach consensus about themes. Further discussion, challenging and explication of themes occurred within the research team. Triangulation (a strategy to increase methodological rigor), was achieved by 1) using more than one case to generate themes, 2) comparing across participant groups, and 3) the inter-disciplinary perspectives of the research team members [22]. We used maximum variation sampling in both participant groups to achieve saturation. Recruitment continued until there was consensus that saturation of thematic concepts had been reached [21]. We employed a dialectical approach to the interpretation of findings.

3. FINDINGS

Thirty-two patients (20 men and 12 women) ranging in age from 49 - 84 years participated. Twenty-nine patients had NYHA Class III HF; three were currently Class II, but had been Class III in the past 6 months. Left ventricular ejection fraction (EF) ranged from 12% - 50%. **Table 1** describes variations in the patient profiles. Eighteen eligible patients were excluded. Of these, 8 said they felt too ill to participate, 5 had language barriers that impeded communication and 5 were not interested. An additional two consenting patients died prior to the interview. The response rate for physician participation was 45%. Nine cardiologists with expertise in HF from five tertiary centers across southern Ontario, Canada participated. Physicians had practiced in cardiology an average of 19 years and their HF practice was currently associated with HF, arrhythmia and transplant services located in five urban centers. Twenty to eighty percent of their practice was dedicated to patients with HF.

Themes

Preferences for prognosis communication were fraught with conditionality. Patients and cardiologists preferred prognosis communication to be individualized, context-dependent and result in a “best approach” for each patient at a particular point in time. Two major themes were identified, each with five descriptive attributes. Similarities and differences regarding preferences did occur within and between participant groups. The themes

and their attributes are presented with descriptions of variations. Importantly, participants said that preferences often existed and emerged in-the-moment as a consequence of a communication interaction. Subsequently, expressed preferences are best understood as both a property and a consequence of prognosis communication as the emergent model will show. In the presentation of findings, “all participants” refers to patients and cardiologists; distinctions about one participant group will be identified as such.

3.1. Theme One: Set the Stage for Prognosis Communication

Ideally, all participants wanted a foundation on which prognosis communication could unfold. This would allow each of the parties involved (*i.e.* cardiologist and patient) to perceive, at the outset and on an ongoing basis, that they had control of the interaction and mentally prepare to engage in and/or deliver prognostic information, and/or to hear and interpret it.

3.1.1. Relational Aspects

The nature of the relationship existing between the cardiologist and patient was central to any interaction. Patients wanted to perceive they were valued and understood by the cardiologist as this patient described:

Like they (the cardiologist) make you feel as if you're important. And I think that's the answer in a nutshell. If they make me feel like I'm important enough for them to be there, that they are trying to do something for me, then I can talk to them. (P112)

Cardiologists wanted patients to understand their particular (cardiology) role in the patient's HF care and that they had the patient's best interests in mind in any conversation.

The existence of a positive and trusting relationship between the patient and the cardiologist was the preferred basis from which all prognosis communication would unfold. Although some said that trust would need time to be established, others said that it could and sometimes needed to be established in a short time, even a

Table 1. Patient characteristics.

Sex	Age (years)	Living arrangement	Highest educational level attained	ICD/Pacemaker (PM)
Men (20)	51 - 79 Mean = 79.7 years	Spouse/partner = 16	Elementary = 10	ICD = 7
		Relative = 1	High school = 6	PM = 3
Women (12)	49 - 84 mean = 70 years	Alone = 3	University/college = 3	
		Other = 0	Post-graduate = 1	
		Spouse/partner = 9	Elementary = 6	ICD = 4
		Relative = 2	High school = 4	PM = 0
		Alone = 0	University/college = 2	
		Other = 1	Post-graduate = 0	

ICD = Implantable cardioverter defibrillator.

single appointment. Patients and cardiologists talked about “sizing the other up”, in essence preferring to anticipate what information was available, required, and how open and ready the other was to information and questions. A cardiologist described this “in-the-moment” approach:

In talking with a patient you make a qualitative judgment as to how much they're likely to accept and trust what you are going to tell them. So the very first time I see a patient may not be the best time for me to talk about that because they don't know me, they haven't developed a trust, and we haven't developed a relationship. (C007)

When cardiologists were consulted for a specific HF-related reason (*i.e.* arrhythmia, transplant), they might not be regularly involved with a specific patient's care, yet new prognostic information may result that could be disclosed. All participants viewed prognosis communication as a cardiologist's duty to initiate and responsibly deliver in ways the patient could understand.

3.1.2. Control

Both patients and cardiologists wanted some control when communicating prognosis and this was evident in various forms. All participants wanted predictions and conversations about prognosis to be open to revision over time so that changes in clinical circumstances could be addressed. Cardiologists preferred to share what they understood a patient wanted, needed, and was ready to know, to select an approach they understood would fit the patient's context and preferably, to anticipate the patient's response. This would influence their choice about what and how information was shared. While some patients valued this approach, others wanted some control over the timing so they were in the best state to “handle it” if the news was not favorable. Both groups preferred to communicate when they perceived openness and receptivity on the part of the other to prognosis conversations. When either party perceived that the other was not open, some wanted the option to defer the conversation. One cardiologist described a combination of factors in which s/he would control (delay) the disclosure of a poor prognosis so that the patient was in optimal condition to receive it:

I've found over time that if you meet anger when you first meet a patient, and thirty minutes into the conversation you're talking about a fifty percent, six month mortality, it often doesn't go over. Sometimes it's better to just say: You know we're going to park that today. And today we're going to talk about optimizing medical therapy and some of the other things that we can offer—monitoring and testing—and then we will bring that (prognosis) back at a later visit, when there's maybe not so much anger. (C001)

Cardiologists who were advocating for an intervention sometimes wanted to use prognosis to support that intervention and subsequently gain consent for treatment.

As soon as we see the heart failure patient for CRT (cardiac resynchronization therapy) or ICD (implantable cardioverter-defibrillator) therapy, prognosis is first and foremost. I mean firstly to explain: Listen, the reason I want to operate on you and put this device in the first place is because your prognosis is poor, and you have a high likelihood of dying from an arrhythmia. The issue of prognosis has to come up immediately to justify what we're doing. (C006)

Patients wanted to know what could be done for them. Physicians said they wanted time to assess the patient's knowledge, understanding and needs regarding prognosis; patients wanted cues from the physician that there was time available to raise issues that related to their prognosis. They perceived cardiologists to be busy and did not want to take up their time with what they thought were not urgent matters. When prognosis communication was deemed by either party to be appropriate and/or of importance in the short term (for instance in introducing a new treatment), all participants wanted time available for those discussions. If appointment time was limited, cardiologists tended to want to defer conversations they anticipated could be lengthy. Some preferred to schedule extra time at strategic points in their practice schedule (such as the end of the day) to discuss a poor prognosis. Some liked to set the stage for very difficult prognosis discussion saying that “next time we are going to review where you are at.

Participants' perceptions about the benefit of prognosis communication at a certain point in time were influenced by the setting in which it was delivered and the patient's current level of physical and emotional wellness. Cardiologists said that they may prefer different approaches for patients who were in hospital. One cardiologist said he felt he had more time to talk to in-patients; hospitalization was also viewed by some as an indicator that prognosis communication was more relevant and necessary than in the out-patient setting because it meant the patient's health status had changed significantly. This combination of factors meant that in the out-patient setting, prognosis communication was potentially relegated to a low priority. However both patients and cardiologists agreed there were times when a patient might be “too sick” to hear their prognosis and to discuss its implications. Some patients expressed concern that conducting prognosis discussions at a time of exacerbation would not be best for them as it would likely interfere with comprehension, as these patients suggested:

I don't understand much when I'm not feeling well. (P111)

I would like to make plans when I am well... I'd make

better decisions. And that would prepare me in some ways for when I wasn't feeling well. (P107)

While having time for discussion was a clear preference, the preferred point(s) in the HF trajectory at which to address prognosis was variable. There was no consensus about when to initiate discussions about the possibility of death. Some cardiologists believed it should be part of the first discussion about HF, others wanted it deferred until there was obvious health decline, treatment optimized and when a patient's lived experience made the patient more likely to recognize the likelihood of increasing disability and death. Patients appreciated the difficulties inherent in formulating a prognosis, yet there was a general preference for beginning those discussions early after the HF diagnosis.

3.1.3. Transparency

Transparency was associated with openness and sharing information that was accurate. Patients and cardiologists said that "truth" was important when discussing prognosis. Truth in this context clearly included the possibility that the prognosis was uncertain, that the exact trajectory for a particular patient could not be known. Patients wanted the option of knowing whatever prognostic information was available to the cardiologist.

I like them (doctors) to be honest... I like to be informed, to know what is going on. (P106)

Prognostic accuracy was valued by both participant groups; concerns about the unpredictability of the HF trajectory influenced the confidence cardiologists had in making a definitive prognosis and, for some patients, in believing what they were told. Cardiologists wanted to convey to patients their difficulty in predicting an accurate prognosis. They generally preferred to base prognosis on a combination of scientific evidence, personal experience with patients with HF, the patient's unique characteristics, results of diagnostic tests and the response to treatment thus far.

3.1.4. HF Treatment Optimization

Cardiologists' preferences for the timing of prognosis communication were influenced by patients' response to treatment and whether treatment was optimized. Cardiologists wanted to focus on what *could* be done. While some cardiologists wanted to delay discussions until therapy was optimized, others liked to use the need for continued treatment adjustments as an opportunity for having prognosis discussions. When improvement occurred, the need for prognosis discussions could be viewed as a low priority, and even unnecessary. Examples of the unpredictability of HF, where patients survived a life-threatening crisis or died suddenly, contributed to hesitancy on the part of many cardiologists to forecast certainty about survival or death. A cardiologist de-

scribed his preference to avoid what he believed to be a premature prognostic statement or one that could prove to be inaccurate in the long term:

I think until they're (fully) treated you really can't prognosticate them very well. You need to see how they respond over time... If you have ten patients in the room, and I tried to guess who was going to do well and who was going to do poorly, I think I would be just flipping a coin. (C003)

3.1.5. Patient Support Available

Patients wanted a supportive approach from the cardiologist, their family, the health team and/or some combination of these resources when prognostic news (especially "bad news") was given. They wanted the option of having their family included in prognosis conversations. Particularly when a patient's condition deteriorated, cardiologists also wanted the patient's support systems included in prognosis conversations.

I would take the lead of the patient (in involving family in prognosis conversations). There are other people involved in their life and other people that need to be aware of the circumstances. So, I think by and large it's better to have a spouse, if that's the person most involved in the care, or the children if they're most involved in the care, aware of the situation. (C004)

3.2. Theme Two: Map the HF Route

All participants understood HF to be unpredictable. Most patients appreciated information that would help them plan for the anticipated and probable illness trajectory, as this woman described:

I want to know well in advance so I can plan for the next step for my life. (P103)

3.2.1. Intentionality

There were differences amongst participants about the need for an invitation to intentionally engage in prognosis communication. Some cardiologists and patients said that intentional, specific, verbal disclosure of prognosis might not always be necessary, when it was perceived by either party that a patient intuitively "knew" their prognosis. For example, one cardiologist explained how s/he believed prognosis was communicated and implicit in the patient's attendance patterns in the HF clinic and therefore did not need to be discussed:

I think at some level you certainly try and make sure that the patient understands that they have a serious condition. It is kind of implicit when they're coming to clinic every month for three or four months and then coming every three months and then every six months, and they're seeing a cardiologist and they're having a bazillion tests. One would assume the patient recognizes that people are worried about them. (C003)

This view was supported by some patients:

I figured something was coming. Cause I figured, I figured on my own, that I wouldn't make it to the hospital. And I also figured that maybe if I do get to the hospital, it'll be the last time I go there. I won't come out. (P41)

Patients did recognize that increasing tests and clinic visits likely indicated their health could be deteriorating; there was some ambivalence about wanting confirmation if this was true.

3.2.2. Nature of the Prognostic Message

Preferences were expressed about the nature of the prognostic message. Some cardiologists preferred the prognostic content to be guided by patient's requests; others wanted to focus on what information they, in their professional opinion, concluded was required at that time. Both groups viewed qualitative prognostic information about the nature of symptom experience as more helpful than quantitative information that focused on difficult to predict life expectancy. The use of statistics to communicate the likelihood of decline or death was favored by some cardiologists. Some preferred to translate those numbers into qualitative terms to help patients understand and make meaning; patients wanted terms and statistics communicated in a way they could understand.

Participants in both groups distinguished between short-term versus long-term prognosis, although no specific times were associated with that. Most patients perceived this as a practical way to think about prognosis, preferring to avoid a discussion in which a time to death was forecast. Most patients understood this to be impossible anyway. Offering a "big-picture" prognosis that considered the patient's co-morbidities, including HF, was viewed as necessary, yet difficult by one cardiologist. Cardiologists preferred to use prognostic time blocks of weeks to 6 months when discussing what patients could expect in the future. For both participant groups, framing prognosis in the short or long term was a way to deal with the unpredictability of HF and a way to communicate hope for survival.

3.2.3. Hope

All participants wanted prognostic messages to be hopeful. One patient likened prognosis information to doing his income tax, saying you don't want bad news and you put it off until you have to do (hear) it. Both participant groups said a poor prognosis could potentially inflict harm by abolishing hope for survival and a good quality of life. There was some reticence by cardiologists to raise what could be perceived as negative prognostic information when a patient's condition was stable because it could communicate hopelessness and frighten patients. Alternatively another said:

I think it's my job to find a way to tell them and to take them through the process. Now, some people might say: Well, I'm removing hope. I don't see it that way. I see it as allowing people to prepare and to do what they wish with the time remaining. (C001)

3.2.4. Coordinated Information

Patients wanted prognosis information coordinated between clinical specialties, practice settings, and practitioners. One patient described why this was the case:

All the doctors, they tell you different things. They turn around everything that the other doctor before told you. It makes me confused. Very confused. I don't know if I'm going to be okay or if I'm not going to be okay or what. I don't know. I don't know what they're going to do to me or if they're going to do anything to me. It just boggles my brain up. And I get all confused and I start getting worried and then... I don't talk. (P113)

3.2.5. Delivery Style

There were varying preferences in both participant groups for the terminology and style of delivery used to communicate prognosis. These preferred approaches were closely linked to maintaining hope for survival and freedom from suffering. Some patients wanted prognosis delivered bluntly and to the point (in unmistakably clear terms) as this patient described:

That doctor, he just told me, he said, if you're not careful, we'll bury you. And I appreciated it. As far as I'm concerned he was totally open. I mean a spade's a spade and that's it. This can happen. If you don't do it, this will happen... and that will happen. (P25)

Others worried this approach would scare them if news was poor and preferred a "soft" or gentle approach that for them was compassionate. There was an overall preference by both groups to frame prognosis in relation to what could be done for the patient. Some preferred to avoid using terms such as "heart failure" and "death" as was evident in this cardiologist's approach:

I don't put the device (implantable cardioverter defibrillator) in to prevent death. I always tell them I do it to prolong survival. It will improve survival by twenty-seven percent. So, I use different wording and always read the patient reaction to what I say. I don't like them to receive this in a negative way. (C007)

4. DISCUSSION

Despite HF practice guidelines that support early and updated discussions about prognosis [3,6,13], it is clear from this study that there is some reticence in their adoption and that on the basis of experience, cardiologists are sometimes hesitant to make prognostic statements that include specific information about decline and death.

The tendency to protect patients from inaccurate prognostication that leads to avoidance and delay of prognosis conversations has been recognized in the past [23]. Cardiologists' concerns about inaccurate prognostication relate to the inexactitudes of individualizing prognosis when extrapolating population-based risk estimates [24]. While patients understood there were risks inherent in HF and in its prognostication, they also valued an honest assessment of their situation, inclusive of those risks [16, 25].

Increasing evidence about the threats to cognitive function for patients with HF provides further impetus for explicit and intentional communication about prognosis [26-29]. The effect of declining physiologic function on the patient's ability to manage prognosis discussions has not been studied in relation to the HF population, but critical questions remain unexamined about the ethics of leaving prognosis discussions until the patient is in a low output state, in which perfusion to the brain is impaired. Patients in this study have clearly expressed that they want to be cognitively able to engage in conversations about prognosis and to act on that information. The only way to ensure this is possible is to make prognosis conversations an intentional part of every patient's care, beginning early after diagnosis and revisited over time.

Knowing that patients were prepared to hear unwanted and uncertain news about prognosis if they felt understood and connected is a powerful argument for a focus on the art and not just the science of medicine. Our findings suggest there is a need to help practitioners talk about prognostic uncertainty and raise difficult and negative prognostic issues throughout the HF trajectory so that patients understand the need for advance care planning in a way that maintains hope for survival and ensure patients do not feel abandoned by their physicians.

Given the number of patients with HF who experience sudden death, failure to discuss death as a real possibility denies patients opportunities they want to plan, even when the future is uncertain [15,30-32]. Leaving prognosis as implicit and/or making unvalidated judgments about what information is worth to the patient also denies patients participation in decision-making. Arguments have been made that patients and physicians collude to leave prognosis unspoken [33]. Yet, the onus to validate the patient's preferences and/or to help create the conditions in which prognosis can be discussed, is arguably on the physician.

Formulating and conveying a prognosis that considers a patient's multiple co-morbidities and that requires care by more than one physician and/or disease-specific specialty demands that someone collates and conveys this information in a way that patients can comprehend [34, 35]. Patients in our study were concerned about these

gaps in information synthesis and flow. Creating time for intentional prognosis conversations is challenging in resource-poor heart function clinics in which cardiologists practice.

This study has identified ten factors which both cardiologists and patients have indicated as crucial to create in practice, a convergence of preferences for prognosis communication. Although these factors constitute only some important elements of the environment in which the complex adaptive system (CAS) of care is provided to patients with advanced HF, they are dynamically interacting with the main players and other elements in the system of HF-related health care. The study data demonstrate clearly that these interactions do not occur in a prescribed linear or sequential fashion. Prognosis communication that is informed by patient and provider preferences is a dynamic interactive interplay in which the stage is set and re-set, and the HF route is mapped and re-mapped. In this iterative way, understanding develops and a preferred pattern of prognosis communication emerges.

The text box lists several of the commonly accepted properties of CAS. Several of these assist in making sense of and enriching the meaning of the ten factors as noted below.

Characteristics of Complex Adaptive Systems

Co-evolution: Context is all-important—the CAS shows ongoing dynamic adaptation to the external environment, constantly exchanging information and energy.

Relationships are vital: as expressed by the interactions and links between agents (participants).

Emergence: Properties or patterns that evolve are more than the sum of the various parts.

Nonlinearity: The interactions of agents and components occur in unpredictable ways and lead to surprising outcomes—not directly in proportion to the strength or size of a factor.

Self-organization: The process by which agents and components interact leading to new patterns of behavior and organization.

Distributed control: Optimal way for the CAS to develop; central control is usually negative.

History co-determines the development of the CAS: Evolution does not occur in a vacuum.

Preferences are contextual

Results support previous findings that indicate there is no single preferred approach with regards to the process and content of prognosis communication for cardiologists and patients with advanced HF [36]. The contextual preferences described here are highly influential for cardiologists and patients as they choose to engage (or not) in HF-related prognosis communication and they must be considered by those who encourage the implementation of any prognostic communication formula [30]. Study findings indicated that cardiologists and patients preferred HF-related prognosis communication to be responsive to the needs of the individual patient and the

contextual nature of the patient-cardiologist encounter.

Without attending to context, preferences for the timing, information and delivery style of prognosis communication can be potentially mismatched between individual cardiologists and patients. This mismatch in approach may result in significant prognosis messages delivered when patients most fear it is useless—that is when they are hospitalized and more likely to be cognitively impaired as a result of perfusion problems and/or side effects of therapeutic pharmacologic interventions. As well as illustrating the concept of co-evolution, these findings also reflect the need for cardiologists to be “sensitive to initial conditions”, another important CAS principle. To put this another way, cardiologists should attend to the contextual “read” through careful listening to the patient.

Cardiologist and patient preferences exist in dynamic inter-relationship consistent with CAS concepts; we found that prognosis communication is preferred to be a dynamic, relational activity from which a preferred pattern of interaction emerges. The factors identified provide a starting point for cardiologists to develop patterns of prognosis communication appropriate for a given HF patient. We had originally thought these preferences would exist as static entities. Instead we have found that preferences exist in relation to other preferences and that they also evolve as they inter-relate. Thus the properties of the whole (in this case prognosis communication preferences) are greater than the sum of its parts (see text-box), another fundamental property of CAS. Kannampalil *et al.* [37] refers to this as the non-decomposability of a CAS; it is essential to examine factor interrelations and not just the factors themselves, if we want to understand the system in which patients and cardiologists exist, and co-create appropriate positive patterns of prognosis communication. As the dynamic interaction evolves, meaning must be made of the prognostic information that is perceived and/or received; patients want to make sense of it in relation to their lives and cardiologists need to adapt to the specific needs and circumstances of the patient.

Preferences emerge and evolve in-the-moment

The preferences that patients with HF and cardiologists described for prognosis communication suggest that such communication emerges from the convergence of evolving thoughts, feelings and knowledge of both parties. The resultant preference at any point of this interaction is that patients feel cared for and their needs for information met; for cardiologists, that their responsibilities as clinicians are fulfilled. Participants described their preferences for prognosis communication as dynamic and subject to change. This reflects and is consistent with communication processes that routinely occur in a CAS. Ideally, prognosis communication emerges and is informed by the converged preferences of both parties.

Both cardiologist and patient have preferences that exist prior to and evolve during prognosis interactions. However, these preferences are often assumed by the other, may be unconscious and may or may not be verified by the other. Ideally, the patient and cardiologist set and re-set the stage and map and re-map the route for prognosis communication iteratively and in-the-moment, as they each make sense of their assessment of the other, the information, and their response. Understanding this can guide clinicians to recognize, respond appropriately to, initiate and engage in prognosis communication with patients even when the prognostic information is unfavourable or uncertain.

Factors influencing preferences converge in unpredictable ways

The conditions inherent in the preferences of cardiologists and patients that exist in a particular circumstance are dynamic and therefore a linear approach to prognosis communication by one participant is not likely to meet the preferred approach(es) of the other. It is this conditional aspect that makes prognosis communication preferences so conceptually difficult to describe and capture. It explains why, when asked about their preferences for prognosis communication, participants commonly framed their preferences as “it depends”. In so doing the participants in this study have provided an essential description of the concept of “nonlinearity”—the way in which many factors, some of which are only partially knowable, combine and interact is conditional and dependent on many other factors. The outcome is often surprising and certainly unpredictable.

We postulate that what “it” (prognosis communication) depends on are the concepts that we have described in these findings—and there may be more that future studies can identify. The combination of factors that exist at a given time in a patient’s life with HF and in the work day of a cardiologist ideally generate a preferred pattern of prognosis communication that satisfies both parties at that point in time. For this to happen, the cardiologist, as facilitator of the prognosis conversation, must listen and be alert for cues from the patient to determine the best approach for a specific patient. This means they are aware of and attend to the issues described by patients. Importantly, this approach does not relieve the cardiologist from engaging in prognosis conversations when the conditions seem less than optimal. It does however honour what patients and cardiologists have said loudly and clearly, that their preferences for the content and process of prognosis communication in the outpatient setting depend on the set of conditions existing in a particular circumstance. They have recognized there are unknowable and unpredictable external influences that could/will affect their future preferences, even during a single interaction. Patients revealed they might not want informa-

tion about quantity of life remaining, but rather wanted honesty (importantly about the uncertainty) and access to information upon which they could make decisions about their everyday lives. This would include letting patients know that the existence of prognostic uncertainty makes advance care planning more, and not less relevant for them [9]. Thus it is paramount that cardiologists are skilled and comfortable in discussing the meaning of the uncertainty in a patient's specific context.

4.1. Limitations

Participants were recruited from an outpatient Canadian population and the expressed preferences of participants may be different from the cultural and practice realities in other settings. Our large patient sample reflected our intent to capture wide variations in patients' ages, illness experience and life contexts. While we were able to recruit cardiologists with a wide range of practice experience in HF, the small numbers of cardiologists who work in HF clinics limited our recruitment numbers. Prognosis communication is only one component of the overall communication that occurs between patient and provider; at times it was preferred to be intertwined with communication about other aspects of care. Thus it was sometimes challenging for participants to identify their specific preferences for communication about prognosis.

4.2. Significance

Preferences for prognosis communication in outpatient HF settings are best understood as occurring within a dynamic and unpredictable CAS. Thus, prescriptive and linear approaches to prognosis communication are both unwanted and unfeasible. Findings offer contextual insights for enacting the recommendations in HF guidelines. Practitioners must have skills for attending to the preferences identified and the willingness/flexibility to engage in a complex, dynamic process. Thematic findings and their application to CAS may be helpful in understanding, describing and advocating for prognosis communication in other medical situations and as a way to help medical students and practitioners think about prognosis communication.

5. CONCLUSION

While effort continues to be focused on the prediction and accuracy of HF prognosis, the findings of this study offer insight about patients' and cardiologists' preferences for communication of prognostic information in the outpatient setting. Practitioners must have communication skills and courage to create and foster opportunities to engage in prognostic conversations even when the prognosis appears uncertain. Fostering practice where prognosis communication can occur in intentional, hope-

ful ways that benefit the patient and that are sensitive to the context of HF is required. Patients require support to ask for and receive news that will allow them to plan for the future if they choose, and to maximize the quantity and quality of their lives. Preferences that aim to protect patients from emotional upset and unnecessary fear and worrying about the future must be examined for their appropriateness to help patients best manage the realities of living with HF. A CAS framework offers a new and enriched appreciation of the complexity of prognosis communication.

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