Preferences of patients with heart failure for prognosis communication

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PH Caldwell, HM Arthur, C Demers. Preferences of patients with heart failure for prognosis communication. *Can J Cardiol* 2007;23(10):791-796.

BACKGROUND: Communication about prognosis is fundamental to discussions and planning for end-of-life (EOL) care for patients with advanced heart failure (HF). Little is known about the preferences of patients that could guide communication about prognosis.

OBJECTIVES: To identify the preferences of patients with advanced HF regarding communication about their prognosis and its implications.

METHODS: A qualitative study using a grounded theory methodology, based on one-to-one interviews with 20 patients recruited from Heart Function Clinic at the McMaster University Medical Centre in Hamilton, Ontario.

RESULTS: The following four main themes about patient preferences were identified: level of wellness – patients wanted to learn about their prognosis and its implications at a time of optimal cognitive function, and not when their capacity for EOL decision making was diminished; opportunity to be informed – patients preferred physicians to initiate discussions about prognosis at the time of diagnosis; tell the truth – there was a strong preference for physicians to disclose prognostic possibilities, treatments and outcomes associated with HF, including the possibilities of deterioration and death; and maintain hope – there was a need for truth to be balanced with hope. Hope for quality of life, symptom control and control over EOL decisions were important to participants.

CONCLUSIONS: The findings suggested that communication about prognosis between patients and physicians may be difficult and deferred. Preferences identified by patients offer guidance to physicians in planning and initiating dialogue about prognosis.

Key Words: Congestive heart failure; Prognosis

Heart failure (HF) is the leading cause of hospitalization in elderly Canadians and is associated with higher mortality rates than some cancers (1). The one-year mortality rate for patients with advanced HF has been reported to range from 40% to 50% (2). Patients living with advanced HF typically experience a trajectory manifested by either sudden death or a prolonged period of decline characterized by recurrent HF-related hospitalizations and worsening symptoms that precede death (3). The literature is replete with descriptions of the inherent difficulties in establishing a prognosis for HF patients. These difficulties arise from two main areas: the irregular HF trajectory, and a societal and institutional health care focus on cure and preservation of life for cardiac patients. These issues have further complicated the challenge of identifying when end of life (EOL) is approaching, as well as determining the time and place for prognostic discussions that have implications for EOL planning.

Les préférences des patients atteints d'insuffisance cardiaque quant aux communications sur le pronostic

CONTEXTE : Les communications sur le pronostic sont un élément essentiel aux discussions sur les soins en fin de vie et sur leur planification chez les patients atteints d'insuffisance cardiaque (IC) terminale. On connaît peu de choses sur les préférences des patients quant aux communications sur le pronostic.

BUT : L'étude avait pour but de cerner les préférences des patients atteints d'IC terminale quant aux communications sur le pronostic et ses conséquences.

MÉTHODE : Une étude qualitative prenant appui sur une théorie ancrée, fondée sur des entrevues personnelles a été menée chez 20 patients traités à la *Heart Function Clinic*, rattachée au centre médical de l'université McMaster, à Hamilton, en Ontario.

RÉSULTATS : Quatre grandes préférences se sont dégagées des entrevues : le bien-être – les patients désiraient être informés du pronostic et de ses conséquences à un moment où ils étaient en pleine possession de leurs moyens cognitifs, et non pas à un moment où leur capacité de décision en ce qui concerne les soins en fin de vie était amoindrie; le moment propice – les patients désiraient que les médecins amorcent les discussions sur le pronostic au moment du diagnostic; la vérité – les patients désiraient que les médecins les informent du pronostic, des traitements et des résultats, y compris des possibilités de détérioration de leur état et de la mort; l'espoir – les patients désiraient connaître la vérité mais, en même temps, avoir de l'espoir. La qualité de vie, la maîtrise des symptômes et le fait d'être maître de leurs décisions en ce qui concerne les soins en fin de vie se sont révélés des aspects importants pour les participants.

CONCLUSIONS : Les résultats donnent à penser que les communications entre les patients et les médecins sur le pronostic pourraient être difficiles, voire reportées. Néanmoins, les préférences des patients, relevées dans l'étude, peuvent guider les médecins dans la planification et l'amorce du dialogue sur le pronostic.

In contrast to terminally ill cancer patients, who have a more linear decline and predictable EOL course than patients with advanced HF, discussions with HF patients about prognosis and EOL planning are often delayed or avoided until death appears imminent (3). When the illness trajectories, needs and health service use of 20 patients with lung cancer and 20 with New York Heart Association (NYHA) class IV HF were compared, it was found that those with HF were relatively more disadvantaged in their ability to discuss and attend to EOL issues (3). Compared with patients with lung cancer, those with HF had a poor understanding of both their illness and prognosis, as well as fewer health services, leaving them isolated, without hope and shielded from the opportunity to plan for EOL care.

While patient preferences for cardiac interventions have received some limited research attention, patient preferences

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Received for publication April 19, 2006. Accepted July 16, 2006

related to prognosis discussions have been left almost completely unexamined in HF populations (4). There is currently little evidence to suggest that prognostic discussions about HF are based on patient preferences for either information or the communication process.

Communication on prognosis is fundamental to, and precedes the development and delivery of, EOL care. The present study identified the preferences of patients with advanced HF regarding communication about their prognosis.

METHODS

A qualitative method using a grounded theory design was chosen. Grounded theory is an approach known for its value for explicating concepts and conceptual relationships relating to a phenomenon about which little is known (5). The study received approval from the local joint hospital-university research ethics board.

Data collection

A purposive sample was recruited from the Heart Function Clinic at the McMaster University Medical Centre (Hamilton, Ontario), a tertiary care university teaching hospital. Purposive samples are commonly used in qualitative research to target participants who are most likely to contribute to an understanding of the phenomenon under study (5). Inclusion criteria were diagnosis of HF, NYHA class III and IV, English speaking and reading ability, no documented cognitive deficits and agreement to a taped individual interview. A nurse clinician at the Heart Function Clinic reviewed the current clinic database using the inclusion criteria. Although NYHA class III and IV patients were targeted, class IV patients on the clinic roster at the time of the study were unable to physically access the clinic. Nurse clinicians who worked with the clinic population were consulted regarding sampling decisions. Maximum variation sampling was used to select participants with variable characteristics who had HF. Maximum variation sampling is recommended to identify general patterns that cross the variations in the sample (6). This resulted in the sample varying in sex, age, education, living arrangements, HF etiology, left ventricular function (LVF) and the presence of implanted devices for defibrillation or pacing. As the study progressed, theoretical sampling was used to recruit individuals who would aid in more fully developing a concept and the link among concepts (5). For instance, it was evident that some participants believed they still had intervention options, such as surgery and/or transplant, that could extend their lives and, as a result, did not view their prognosis as terminal. Sampling was targeted to recruit patients who were on optimal treatment, not candidates for more interventions and who may consequently have had different preferences for hearing the truth about their prognosis.

Potential participants were contacted by a research assistant, and the study was explained. Of the 28 patients approached for interview, eight refused. Three men who refused were not interested in research and one man had difficulty with the English language. They had similar demographic and medical profiles to those who participated in the study. One woman and two men did not feel well enough to participate, and it is possible that increasing symptomatology might have made their responses to interview questions different from participants. One patient died before a scheduled interview. The remaining patients who consented to an interview met the interviewer, had the study further explained and provided written, signed consent.

The semistructured interviews were conducted by the first author of the present paper, a doctorally prepared nurse with expertise in qualitative research methods and interviewing. One-to-one audiotaped interviews were conducted in a room near

the Heart Function Clinic and lasted up to 1 h. Because it was possible that participants had not had conversations with their physicians about their prognosis, the interviews began with general questions such as, "Can you tell me what living with HF has been like for you?" and, "Has your doctor ever talked with you about how heart failure might affect you in the future?" If participants did not have any prognosis conversations, they were asked questions to explore their preferences related to such potential conversations. As the interviews progressed, questions included details about the timing, content and context of the preferred prognosis discussions. This approach enabled the interviewer to probe individual responses in a way that did not cause alarm about the possibility of functional decline and death. References to the possibility of death and dying were left to the participants to bring up as they felt comfortable or deemed relevant, and all participants raised these issues on their own early in the interview.

All participants said they agreed to be interviewed because they viewed it as helpful for others diagnosed with HF. Following the interviews, some participants disclosed that the interview had provided a much appreciated opportunity to reflect on issues that were important to them, but that were seldom, if ever, discussed.

Data analysis

An audit trail was maintained that documented all study activities, including detailed notes about the analysis process. Data collection and analysis occurred simultaneously. Interviews were transcribed verbatim by a transcriptionist and checked for accuracy against the tapes by the interviewer. Postinterview notes and a reflective journal were maintained throughout data collection and analysis. Together with the transcripts, these notations were used in debriefing sessions with a cardiovascular nurse scientist and a cardiologist with expertise in HF. These analytical processes developed interview questions with each subsequent participant, and validated and developed evolving theoretical concepts.

Data were analyzed using the constant comparative technique. Coding was performed independently by two researchers with line-by-line manual coding. Microsoft Word (Microsoft, USA) files were created to label and manage codes. Memos were kept regarding theoretical concepts emerging from the data and the possible linkages among concepts. Themes were determined during researcher meetings, when codes were compared and discussion occurred on whether and how patient statements related to an emergent theoretical construct. For instance, 'truth' emerged as a recurrent issue from the first interview onward. What constituted truth for patients, and the antecedent and contextual conditions for disclosing the truth, were compared between researchers. If consensus was not attained regarding a code or theme, the researchers returned to the data to reanalyze and formulate further questions for review with the participant, or for exploration in future interviews.

Recruitment continued until saturation of themes was evident. This was achieved when all data were accounted for in the established themes, and when themes and their connections were sorted and compared to clearly explain patient preferences. Data were reviewed and compared with proposed thematic relationships until the researchers agreed that it reflected the contextual nature of patient preferences for prognosis communication.

RESULTS

Twenty participants (14 men and six women) participated in the study. Patient age ranged from 50 to 84 years (mean 68 years). At the time of the interviews, 17 participants were in NYHA class III; three men evaluated at that time as being in class II had recently

been in class III, had low LVEF and had an implantable cardioverter defibrillator (ICD). The LVEF for the sample ranged from 12% to 50% (mean 27.7%). Fifteen patients (three women and 12 men) lived with a spouse or partner. Seven had completed elementary school, 10 completed high school and three had a postsecondary education.

The preferences for communication about prognosis were described primarily within the context of what participants referred to as a 'day-to-day' existence. As such, their focus was on short-term survival, while at the same time trying to stave off the possibility of decline or death. It was within this social context that preferences regarding communication about prognosis were formulated and elicited. Based on their experiences with HF, participants believed that they lived in a culture of prognostic uncertainty. Perceptions about the roles played by members of the health care team influenced participants' expectations about the content and process of prognosis communication. While participants consented to discussing their preferences for the purposes of the present study, they expressed doubts about the likelihood that their preferences could influence care.

Four themes were identified to describe patient preferences for prognostic communication. Themes described 1) contextual communication factors related to the level of patient wellness and the opportunity to be informed and 2) the content of prognostic communication; that is, the preference for physicians to tell the truth and maintain hope.

The theme labels were derived from patient statements embedded in the data.

The basis for prognosis communication was an optimal level of wellness. If patients perceived themselves physically and mentally able, they would be amenable to be informed about their prognosis. This included the timing and delivery of information, as well as pursuing or declining an opportunity based on what they perceived to be their need and level of wellness at a certain time. If patients were 'well' and the opportunity arose, they wanted prognostic communication to be delivered truthfully, but balanced with a message of hope.

Level of wellness

The level of wellness referred to a patient's preferred optimal physical and mental state for engagement in prognosis communication. All participants associated HF with loss and decreased function. Concern was expressed by many participants about the possibility of decline resulting in cognitive impairment, which would interfere with their ability to process and manage prognostic information. There was a stated preference for discussion of prognosis and its implications at a stage of the HF in which patients were mentally alert and had the most energy. One man outlined the potential dilemma posed by delaying such discussions: "I think you should [discuss prognosis] you know, before you get so bad that you don't really know. Because you can get bad that you don't know really what's going on".

There was a tangible need for participants to maximize their functional abilities and assume as much control as possible over their lives. They perceived that they had most control when HF symptoms were well managed and they felt relatively well. Concern was expressed about the effect that chronic fatigue and activity restrictions may have on the individual's ability to engage in EOL planning, if such decisions were left for a later stage in the illness.

Participants wanted to be able to make EOL plans before they were too ill to do so. Although those interviewed had done some planning on their own, there was an expressed preference for

someone to 'plant the seed' when they were most well. One woman described her need to be informed before she was debilitated by HF:

I would like to be able to take control of my life, not have no control. If they know that your heart is deteriorating and that there is a good possibility that you are not going to respond very well to medical therapy, and so maybe three, four years, maybe two years and you probably may die, but if you don't, your life is severely restricted, then I would like to know that. I would like to know that time period that I have the strength and energy to do things. I would feel very cheated if I wasted that time and then I was in that position or I died, but I was in the position where I couldn't do any of that, to know that other people had suspected or knew that would be probably going to happen.

Participants preferred to discuss prognosis on days when they were more resilient and in control of their response to conversations about prognosis and its implications. One woman's preference for prognostic information was based on the resilience she perceived in herself and her physician: "That depends on how I'm feeling that day. That's the only thing I've noticed about myself is that sometimes I can handle a lot, you know, and I know it; I know that I can handle it, but they [physicians] do not like the show of emotion".

A paradox emerged regarding preferences for prognosis communication and level of wellness. Although participants recognized that they were better able to manage prognosis discussions when they were well, they also said they may not want to think about implications of a negative prognosis at that time. Alternatively, when they were ill, they had concerns about being mentally, emotionally and physically able to engage in such discussions and process that information.

Opportunity to be informed

The theme 'opportunity to be informed' described patient preferences relating to the time of the prognosis communication. There was a general preference for patients wanting to know about the prognosis 'right away' (ie, at the time the diagnosis was made). This was true particularly among those participants who only came to know about the course of HF when they experienced distressing symptoms and/or deterioration in their overall condition. Most participants wanted to know whether further change or deterioration was occurring or could be predicted in the upcoming months. One woman offered an example of a conversation she would find helpful in this situation:

"Your heart is deteriorating. We can increase some of this medication". And I feel I have the right to know that too. "You are going to be comfortable, but you will be limited in your activities. You'll probably be tired a lot more than you are now". To not be told and to have all that happening would be more frightening.

Some participants referred to the uncertainty of living with HF and wondered whether they had a future. Among these participants, there was some ambivalence as to how much prognostic information they preferred to know. Some suggested the need for time to absorb prognostic information and have opportunities to explore it over time. This reflected a preference in participants to have more than one opportunity to discuss the implications of prognosis.

Participants wanted an environment that they perceived was open to the possibility of exploring prognosis. When participants

wanted prognosis information, they were sometimes hesitant to ask for it. The discomfort that accompanied the prognosis discussions was captured by one participant, who protected his physician and himself from engaging in such an interaction: "And feel that I don't want to ask the questions because I don't want to put my physician on the spot; put them in an uncomfortable position".

When participants requested information from their physicians about prognostic likelihood, they did not want the matter to be avoided. Some perceived prognosis discussions were 'taboo'. One woman described her experience of this taboo as she pursued information relating to her prognosis with an ICD:

They put the defibrillator in, and I asked my doctor [about the prognosis]. He was telling me all about the good points and bad points, and I said, "What happens if I outlive the battery?" "Oh," he said, "that's no problem; we'll just give you a new battery". So he wouldn't tell me either. Then I asked him was I going to live long enough to – he said the battery lasts seven years. I said, "Oh, does that mean I'm going to last seven years?" And he said, "No, if your battery runs down, you get a new one".

A preference was expressed for physicians to initiate discussions about prognosis. Patients described that when they were referred to a cardiac specialist for revascularization, valve repair or arrhythmia management, and no therapeutic intervention could be offered, prognosis communication tended to be one-way, from specialist to patient. The following quote reflects a participant's frustration about how he perceived compartmentalized cardiac care created barriers to effective prognosis communication:

They look at one thing and one thing only: whatever they specialize in. So you're running from one specialist to another. But ah, basically, its [patient pauses] no one seems to be able to say, "Well, um, this is it". They defend themselves and their profession too much.

A strong preference was expressed for all patient-physician communication about prognosis to be a two-way conversation. Opportunities were preferred for the discussion of the prognostic implications arising from referral outcomes and recommendations.

Participants preferred an environment that was conducive to conversations during which they could initiate and explore their prognosis, if they so chose. This was challenged by the perception that because of demands on their practice, physicians did not have the time to discuss or respond to their questions. Participants thought that physician interpersonal skills influenced their opportunities to explore a prognosis. Preferences were expressed for a physician with inviting and supportive communication skills.

Most participants wanted control over which prognostic information was shared and with whom. This often arose from a concern about their family's ability to manage the information:

I know a lot of the people that the doctors all talked to the wife [of the patient], because she's in better shape than he is, won't tell him what's going on. Well, I say, 'You tell me and then I'll decide if I want to tell the wife'.

Communicating prognosis with the patient before sharing it with others was also viewed by some as a way of maintaining normalcy in their lives. One participant described how normalcy was compromised when family members feared the prognosis and were overprotective:

I think [knowing the prognosis] would be, it would be so hard on them, that they would make my life miserable. It would be like "Don't do this, don't lift this..." I don't like

that. I like, I used to yell, "Just leave me alone, I'll tell you". And I've said to my husband, "You know, sometimes, if I have a little pain, I wouldn't even tell ya because I don't want you sitting there watching me every two seconds," you know. So I would like the information, and I would like to be able to make the decision of who I tell. If I felt that my family needed to know, then I would make the decision that I would tell them or ask the physician to tell them after I digest the information, make some decisions.

Tell the truth

Participants stated a preference for wanting to know the truth about their condition and what the future was likely to hold. The 'truth' was held to be the physician's honest and best judgment about the actual and potential risks and outcomes associated with HF. There was a belief that physicians were obligated to share that information with the patient:

Well, if they think that you are not going to get better, they should give you the choice and let you know. I think it's their duty to tell you. I mean, there is no sense in going to the doctor and he saying, "You're okay," and you're going to die tomorrow. I would rather they tell me that. At least then I know what they think.

Knowing the prognostic possibilities was viewed as helpful for participants to make decisions about living situations, finances and personal planning, such as living wills or advanced directives. 'Telling the truth' included introducing the possibility of deterioration and death; this was a comfortable topic for some, but not for others:

I understand no one can really say. Okay, I understand, but that's not really fair either. Maybe you'll live longer [than they predict]. But I think it should be said. It should be said. You feel you want to put your life in order, but you can't seem to be able to do it because you don't have no – you don't have a clue. Are you going to be around in a year or two? Should you make plans? Should you not? Why can't they stop the deterioration in my heart? At first, you want to know every detail, so you try to get information to tell you and then you get to the point where you feel 'I don't really want to know,' but you do; you do want to know. To get your things in order. Get your life in order. Plan. Am I going to end up in a hospice or something? And, how am I going to pay? That kind of thing.

Participants preferred to know the treatment options available to them, as well as the possibilities and realities (positive and negative) associated with those options. Options raised repeatedly by study participants included coronary bypass surgery, valve repair, ICDs and heart transplantation. Being presented with treatment options provided an indirect way for patients to understand the severity of their health status. As options ran out, patients came to understand that deterioration and death were more likely. However, even though patients could deduce these outcomes, they still preferred that a physician confirm their beliefs so that EOL planning could be considered seriously.

There were preferences expressed for the manner in which the 'truth' was revealed to patients. Participants preferred physicians to be direct in their communication. Being direct referred to the use of explicit and/or euphemistic language that would be understood by patients as prognostic information. Euphemisms were appreciated as gentle ways of communicating information while avoiding the use of terms such as 'die', which participants and

physicians may find difficult. Terms and statements such as 'deterioration', 'if you're not careful, we'll bury you' and 'the name of the game is keeping you alive' communicated the fragility of a patient's health status without sounding hopeless. While participants liked this approach, its use was dependent on the communication skills of the physician. If not used well, euphemistic language was interpreted as the avoidance of truthful prognosis discussions.

Maintain hope

Although participants wanted the truth about their prognosis, there was a need to have the truth balanced with hope. The potential for invasive treatment options to offer hope for increased quantity and quality of life was a message participants wanted to hear. When no further invasive interventions could be offered, they preferred to focus on the short-term prognosis and the hope for a good quality of life on a daily basis. In the longer term, these participants wanted to know that symptoms could be controlled and that death would be dignified. Many participants preferred to discuss their wishes for resuscitation and substitute decision making with their next-of-kin, but there was no consensus about whether or how to communicate with physicians about these issues.

There was a stated preference for instilling hope in any prognostic message. One way this could be achieved was to help patients see the role they could play in maintaining health. This was valued as a way of giving participants some feeling of control in a situation in which they often felt they did not have control.

Several participants had been told that there were no treatment interventions available to them for improving their cardiac function. Clearly, this was information no one wanted to hear, even though they recognized that this may be necessary for them to know. Participants valued being reassured that distressing symptoms, such as respiratory distress, could be relieved if they had an exacerbation. Of importance in such situations was that there was hope for symptom control.

Communication about a negative prognosis without the simultaneous provision of hope was perceived as destructive to the patient-health professional relationship, as illustrated in the following quote:

The way they put it, I was just about dead. They just told me I had heart failure. Couldn't do this, couldn't do that. And they just sent me home. I was left hanging in the air at that time. I wasn't told that "Oh, you can live on for years and years. We can control it". I wasn't told any of that.

DISCUSSION

Patient preferences for communication about prognosis raise questions about the place of prognosis communication in the HF trajectory, the realities of the practice milieu in which care is provided, the skills of those who engage in such interactions and the philosophical approach to the care of patients with advanced HF.

Participants expressed concerns about their abilities to process and respond to information if they were experiencing a cognitive and/or physical decline. The etiology of cognitive decline in HF is not well understood or routinely assessed (7). Patients' concerns, however, suggest that there is reason to consider the place of prognosis communication in relation to the HF trajectory. The effect of declining function on a patient's ability to manage prognosis discussions has not been studied in relation to the HF population. Participants in the present study were interviewed at a time when

they were medically stable. Patients suggested that it was possible their preferences could change in relation to the changes in physical and cognitive function that occur in the course of the disease trajectory.

A metasynthesis (8) of research studies that examined the lives of patients living with a chronic illness has suggested that patients' perspectives about their lives may change after periods of increased acuity. This Shifting Perspectives Model of Chronic Illness proposes that when chronically ill patients, such as those living with advanced HF, feel most well or have 'bounced back' from a crisis, they may prefer to avoid an illness perspective; the very perspective that may foster communication about prognosis or its implications. This paradox was identified by some study participants, indicating a need to establish if patients with HF have different perspectives and preferences for prognosis communication as they move between perceived wellness and illness. The relationship between events in the HF trajectory, the patient's perspectives about their lives, and their desire and ability to process and act on information about prognosis at those times requires further investigation. Future research regarding preferences for prognosis communication should be examined with reference to the point in the HF trajectory and in relation to the shifting perspectives model.

There are complex challenges for physicians in establishing a prognosis and in recognizing, responding to or advocating that patients know their prognosis and its implications. For prognosis communication to occur as patients prefer, time must be available within the practice context. Given the chronic nature of HF, communication about prognosis may not be perceived by either physicians or patients as urgent when viewed in relation to immediate management issues. However, it is arguably necessary for patients to have the opportunity to plan for their futures and to have some control over how their lives will be lived out.

It may be that clarity is lacking on the roles of the physician and other health team members in discussions about prognosis and its implications for life planning. When patients are referred to other cardiac specialties, role confusion is increased and responsibilities for conveying prognosis appear particularly unclear.

Findings in the present study indicating a preference for prognostic communication that is both truthful and hopeful were similar to the preferences identified in a survey of patients with incurable metastatic cancer (9). These preferences have implications for the interpersonal skills of the practitioner caring for patients with HF. A physician's approach to HF as a treatable chronic illness (10) and to death as treatment failure has been suggested as contributing to the delay or avoidance of discussions about prognosis (3,4). The examples of avoidance provided by participants are consistent with those findings. These examples may illustrate what Quill (11) referred to as "the unacknowledged elephant in the room", in which patients and physicians avoided discussing death, even when, and perhaps because, it was the most obvious and feared outcome. Physician worries about generating hopelessness in patients have been noted to make them hesitant to communicate a negative prognosis (12). Recently, the case for 'necessary collusion', in which prognosis is understood but unspoken between patients with advanced cancer and physicians, has been posed as an ethical approach to prognosis communication (13). The use of euphemisms to communicate prognostic information may reflect collusion. Further examination of this phenomenon in patients with HF is warranted. Clearly, there is a need for leadership to foster development of a care environment in which discussion about prognosis is initiated and patients are enabled to develop and act on choices for (end of) life.

Philosophical questions were raised in relation to the impact of technological options, such as ICDs on prognosis communication. Although interventions to increase the length and quality of life offer hope for patients with HF, there is potential for them to veil the prognosis and its implications.

There are limitations to the present study. Participants were recruited through a Heart Function Clinic, and it is possible that their preferences did not reflect those of the larger population with advanced HF. The study population was white, mostly male and cared for in the publicly funded Canadian health care system. Findings may not reflect sex or cultural variations in preferences about prognosis communication. Given that only those patients who perceived that they were well enough to participate in an interview were included in the study, it may have been that

their preferences differed from those who perceived they were more unwell. It is also possible that the perceived relevance of prognosis communication and study participants' preferences for it may have been influenced by illness exacerbation close to the time of the interview.

CONCLUSIONS

There are indications that prognosis communication presents difficulties for both patients and physicians. Study participants wanted the opportunity for intentional, two-way, honest and up-to-date communication regarding their prognosis at a time when they could cognitively process it, and they preferred that it was delivered with compassion and hope. The depth to which participants wanted the implications of prognosis explored varied.

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