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**LIFE AND PRIORITIES BEFORE DEATH: A NARRATIVE INQUIRY OF UNCERTAINTY AND END OF LIFE IN PEOPLE WITH HEART FAILURE AND THEIR FAMILY MEMBERS**

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**ABSTRACT**

Background: Most patients with advanced heart failure (HF) are ill-prepared and poorly supported during the end of life (EOL). To date, research has focused primarily on generalized patient accounts of the management or self-care phase of the syndrome. Little research has examined EOL in depth or from the perspectives of family members.

Aims: To describe how people diagnosed with HF and their family members describe uncertainty related to impending death.

Methods and Results: A narrative inquiry was undertaken using a social constructionist perspective. 20 participants took part in over 60 interviews: 12 participants with HF (8 male and 4 female; mean=67.3 years) and 8 family members (mean=61.6 years) engaged in two in-depth interviews, approximately three to four months apart, followed by a telephone follow-up two to three months later. Six key themes/storylines were identified. These included: *prognosis messages received from physicians; whenever I die, I die; loss isn’t new to me but….; carrying on amidst the fragility of life; ultimately living not knowing; and the need to prepare.*

Conclusion: The six key storylines of death and dying with advanced HF were consistent for both patients and family members. There was a desire for better communication with physicians. Many participants were critical of how the prognosis of advanced HF was communicated to them, even if they anticipated the news. Participants wanted frank, open conversations with their health care providers that both acknowledged that they were at EOL but did not remove all hope.

**Keywords:** heart failure; family; chronic illness; narrative inquiry; qualitative research; end-of-life

**Introduction**

Heart failure (HF) affects up to 37 million people worldwide [1,2]. This common and burdensome syndrome is present in 40% of those over 85 and in 10% of people over 65 years [2]. Almost half of those with HF die within five years of initial diagnosis [3]. Many are ill-prepared and poorly supported during the end of life (EOL) [4,5]. This is a result of a lack of dedicated palliative care services for HF patients [6], ongoing dominance of ‘curative’ approaches to HF care [7], discomfort of healthcare professionals in providing EOL care in cardiac settings [8], and the general uncertainty associated with the HF illness trajectory [9].

Research into patients’ accounts of HF, although now large in terms of the number of studies, has focused almost exclusively on general accounts of patients’ experiences, particularly in the disease management or self-care phase of the illness [10,11]. During this stage, patients seldom recognize HF as a life-limiting diagnosis or that the end point of HF is death [12,13]. Patients also perceive that health professionals are reluctant to discuss EOL issues and decisions with them [14,15]. The reasons for this reluctance are not entirely clear. In one study conducted in Sweden, many nurses reported that they were knowledgeable about EOL care, but 69% of them thought that physicians should have the main responsibility for communicating with their patients about prognosis and 67% thought physicians should have the main responsibility for communicating with patients about EOL care [15].

Lack of communication is concerning not only due to the prevalence and degenerative course of HF, but also because patient accounts at EOL are substantially different than those during earlier phases of the illness. For example, HF is associated with worsening fatigue, dyspnea, and exercise tolerance as the disease progresses [16]. Furthermore, daily symptoms and anticipated life expectancy are uncertain with high stress and anxiety for the family or other caregivers [17,18,19].

Despite the fact that clinical guidelines outline the importance of integrating a palliative approach in HF care [20,21], the optimal interventions or aspects of a palliative or supportive care program are unknown. Hence, the integration of EOL care into existing HF disease management continues to be a challenge [22]. A better understanding of the experience of advanced HF for those with HF and their families could enhance care and elucidate important elements of supportive care for this population.

**Uncertainty** is inherent to all advanced chronic illnesses including advanced HF. Mishel [23,24] described a theory of uncertainty in illness first in relation to acute illness and later extended it to chronic conditions. Mishel’s theory pertains to cognitive appraisal and perceived uncertainty of illness. The key elements of uncertainty management include information, patients’ ability to make sense of that information and their potential to use it to take an active part in decision-making [23,24].

This study explored the perceptions of uncertainty of people with advanced HF and their family members over time around EOL issues and healthcare. It was part of a larger study of uncertainty of people with various advanced chronic illnesses approaching EOL [25]. Better understanding is needed of the experiences and uncertainties of people with advanced HF and their family members to provide better EOL care.

The research questions were**:**

1) How do people diagnosed with advanced HF describe uncertainty related to impending death?

2) How do family members describe the experience of caring for a person diagnosed with HF and living with the uncertainties of impending death?

**Methods**

**Design**

A qualitative narrative inquiry using a social constructionist approach was used. In-depth interviews were undertaken to explore people’s experiences of living with the uncertainties of advanced illness and the likelihood of dying. This method acknowledges that understandings and experiences of reality are sustained and shift over time through stories [26,27].

**Participants**

People with advanced HF and family members/significant others were purposively recruited through two western Canadian hospitals. Participants were identified by nurses in the HF clinic. The inclusion criteria were: over 18 years of age with exacerbations, New York Heart Association Class III or IV HF, complications or notable progression of disease and one or more co-morbidities. Exclusion criteria were:non-English speaking persons; significant cognitive impairment; and acute distress related to the diagnosis. Participants were informed that the research focused on the uncertainties of living with a serious illness. This focus enabled us to begin the discussion of death and dying in a non-threatening way. In one centre, names of people meeting the inclusion criteria were given to the research team and in the other, potential participants were left with an information sheet inviting them to contact the research team. These differences in recruitment strategy were related to the different processes the two health care organizations had relating to accessing participants. Because of the latter recruitment strategy, it is not clear how many potential participants declined participation.

**Ethical considerations**

This study complies with the Declaration of Helsinki. Ethical approval was granted by the Institutional Review Boards of the educational institutions; administrative approval was obtained from appropriate health care agencies. Participation in the study was voluntary. Written informed consent was obtained at the time of the first interview. Pseudonyms were used to protect confidentiality of participants and confidentiality between members of the dyad was preserved.

**Data collection**

Data were collected between September 2016 and September 2017 in two in-depth interviews, approximately three to four months apart, followed by a telephone follow-up approximately three months later. Due to the number of interviews and two geographic regions for the study, five interviewers (one investigator, two doctoral students and two research assistants) conducted interviews. All interviewers were female and experienced interviewers; two of the interviewers were nurses and others had preparation in other health disciplines. The interviewers furthered their narrative interviewing skills through training workshops and dialogue with the research team. Weekly debriefing sessions between the interviewers and the investigators facilitated training, quality and familiarized the team with the data. Dialogue among the team members enabled them to obtain informal feedback, consider strategies for interviewing and gain support after emotion-laden interviews. Members of the research team held no prior relationships with the participants.

Twelve people with advanced HF and eight family members participated in the study. Participants with HF had a mean age of 67.3 (range 55 to 84, 8 males, 4 females). In the screening process, participants were asked to identify a family member (or significant other) who would be interested in participating. They were not excluded if they did not have or chose not to identify a person. Family members, had a mean age of 61.6 years (range of 54 to 76 years). Six of eight family memberswere female and included six spouses and two adult children.

The first two interviews were face-to-face and each interview took approximately 90-120 minutes. Although the interviews were long, participants were very engaged in the discussions and did not report fatigue. Interviewers periodically offered to come back at another time, but participants opted to continue. The third interview was a follow-up telephone conversation approximately 20-30 minutes long and focused on clarifications and closure. All interviews were held at a mutually convenient time and location, usually in the participant’s home. Whenever possible, participants in the dyad were interviewed separately to provide the opportunity to speak freely and confidentially. With three people with HF, the family member was present for part of the interview at the request of the person with HF. All family members were interviewed privately. Interviews were semi-structured, began with broad general questions such as ‘Tell me about what it is like to live with a serious illness’, followed by questions guided by the specific comments and stories of the participants as well as the study objectives (see Table 1 for Sample Questions). Immediately after the interviews, field notes focusing on context of the interview, changes in disease condition and nonverbal communication were recorded and transcribed.

All interviews were audio-recorded and transcribed by a professional transcription company. The interviewer verified and corrected the transcripts before analysis.

**Data analysis**

Riessman’s [28] approach to thematic analysis within and across participants (person with illness and family members) was used. The research team read and re-read the transcripts and listened to the interviews. Final coding was conducted by two research assistants under the supervision of the research team. Differences in coding or questions about categorization were discussed until consensus was reached in the entire team. N-Vivotm Version 11 software was used to code the transcripts. Theoretical saturation was achieved when no new themes were identified. These themes were consistent across most participants’ transcripts.

**Rigour**

Credibility, transferability, dependability and confirmability were examined to demonstrate the trustworthiness of the research process. Credibility was established through prolonged engagement with the participants who were purposively selected for the purposes of the study. Field notes were recorded after each interview. A detailed audit trail [29] was maintained; records of all design and data analysis decisions were recorded, including the theoretical and process memos of analytic decisions. We did not return transcripts or verify themes with participants because of disease progression and related changes in perceptions of illness over time.

**Results**

**Themes/storylines emerging**

People living with advanced HF, and their family members, described the uncertainties of impending death with surprising consistency. These included: *prognosis messages received from physicians; whenever I die, I die; loss isn’t new to me but….; carrying on amidst the fragility of life; ultimately living not knowing; and the need to prepare.*

***Prognosis messages received from physicians***

 HF participants reported shock in response to receiving the initial ‘news’ about their prognosis from physicians. Other health providers were not mentioned by our participants. Rita, 55, was told that she would not survive a year, and reported her physician was *“very blunt. Very, very blunt.*” She recollected that he told her to “*go home and live your life – whatever’s left of it….”* She went on to say, “*I wasn’t denying it. But I was thinking, ‘hmmm. But people get better*.’” Conversely, Amanda, a 60 year old woman’s physician told her that “*you’ve had a lot of good years – you were very young when you started*…” but when Amanda bemoaned that, “*I probably won’t even live ‘til I get a pension cheque*”, her physician wouldn’t engage in the discussion saying, “*Oh, don’t be saying that! You’re gonna live a long, long, long time.*” Participants concluded that the physicians were trying to create distance, recognizing that the patient would die soon.

People with HF acknowledged the importance of their physicians. Wayne said: *“I’m not gonna do anything to piss her off…. I’m sure I’d have been dead four years ago, or five years ago, if it wasn’t for her.”* Samantha, a spouse, talked about her visit with their physician: “*he said, ‘you know, no one knows your mortality. We don’t – no one knows…”* This gave her hope.

***Whenever I die, I die***

In most cases, participants reported readily accepting their prognosis and the closeness of death. Wayne, a 67 year old man who had a long history of heart disease, talked about adjusting quickly noting, “*It bothered me for a day or two, and then I just – do what we gotta do and I guess that’s the way I always looked at it.*” Similarly, Philip, 78, said, “*Whenever I die, I die. …And I’m not afraid of it. Well…when it’s my time, it’s my time.*” Corinne, a 61 year old wife noted:

“We deal with death every day. We don’t have a choice. And our humour is what gets us through. The last six months at least have been really tough. Because I have seen so much of a change in him physically, that um...his death is staring me right in the face.” (Corinne)

However, there were exceptions. Amanda, a 60 year old woman with valvular disease was less accepting. She said that “*I think it’s that end-of-life um, that is – is a little bit of a bother, you know? Cause I guess, mentally, I’m not there… I think that brings me down thinking of it in terms like that*” despite the fact that she said, “*I was told right from the get-go that you will probably die of heart failure.”* She continued, “*where am I now? Umm, I’m not sure where I’m at – I think that I have a death sentence*”, adding about the “*big D – you know the big denial going on there*.” Her partner, on the other hand, said, “*If it happens tomorrow, we’ll…that’s just the way it happens.*”

The main concern for many of the participants related to becoming a burden at the EOL. Philip saw one way to alleviate the burden and commented, “*the assisted dying, I’m a hundred percent for it.*” His wife was concerned about how she would manage both his care and her future, because she was so dependent on him. “*And where do I go from here…`if I…couldn’t handle him anymore, he has to go to a nursing home, what would I do* [getting teary]*?*” She described a recent fall that Philip had in the bathroom, making her “*more paranoid*.” Similarly, Loretta, like many participants, longed for an easy death rather than lingering and being dependent on others. She said:

“Okay well, if I die tomorrow, let it be or whatever. I mean the worst thing - I have a fear that I would end up in…with a severe stroke, be paralyzed on one side, be unable to take care of myself. More or less be bedridden and whatever. And I would rather just pass and not have that.” (Loretta)

***Loss isn’t new to me but…***

Most of the HF participants reflected on other losses and how these influenced their perceptions about death. News of their prognosis was linked to reflections on participants’ own family history with heart disease and deaths. Amanda compared her potential life expectancy with her mother’s but knew that was a “*fantasy*”. Her husband also talked about how “*this isn’t new to me*” and referring to other losses, “*it* [wife’s prognosis] *is just … another incident.*” Yet, he also commented that Amanda “*takes it a little bit too close and heavy and I’m more matter-of-fact*.”

Participants thought about how they wanted their own death or family member’s death to be different from others they had witnessed. Britney, a daughter, wanted her father’s death to be different from her mother’s given how she [the mother] “struggled to breathe” at the end. Lester, an 84 year old widower with HF talked about how a number of people around him died. Regarding his wife’s death, he said, “She was really *gurgling and that, and ah…they were giving her quite a few shots of morphine and so on and then one day I was there… and she just… stopped breathing…That was rather traumatic, watching your wife die.*” This was in contrast to his sister’s death who had been working when she became ill: “*and went to her bed. And passed away. And she wasn’t found for seven days*.” He talked about these deaths in considerable depth commenting, “*it makes you think*.”

Family deaths and losses provided opportunities for participants to discuss questions relating to death and dying with their significant other. Loretta, after talking about her mother’s death and her cousin’s son’s stillbirth said, “*even my husband…he said ‘okay well, um…do you wanna be buried or do you wanna be cremated?*’ And when she confirmed cremation, he said, “‘*okay now, do you wanna…you know, us to keep your ashes in an urn at home or do you want us to place you somewhere?’ Where we’d never talked about anything like that before.”* While participants were familiar with loss, their past experiences both informed how they faced their own mortality and were distinct because it was now their own experience.

***Carrying on amidst the fragility of life***

Beyond being told and seeking to come to terms with their prognosis, most of the participants reported focusing on living as well as they could despite their limitations. Lucy, a 70 year old woman, noted that there were many aspects of her condition that reminded her of her frailty and the “*fragility of life*” but she tried to “*exercise my energy each day the way I want to and as much as I want to. And not worry about dropping dead*.”Mick found that he had to put a lot of energy into “*just staying alive*.” Referring to maintaining his health, he said, “*It seems like an overwhelming job sometimes*” and the effort needed made it virtually impossible for him to leave his house. Family members particularly talked about impairments in quality of life. Petra discussed how they could no longer travel because Philip was unable to qualify for travel insurance. They also missed boating, camping and going to the lake.

Participants also reported seeing life differently. Amanda talked about how her visits to friends took a “*different twist*.” “*They’re like more important. Um, I leave – I don’t know if I’ll be back…I never thought that way before.”* In relation to going back to work, she said: “*I have to really weigh that out, if that’s good or bad. It’s good for the clientele. But do I wanna go back to the old boss ways? Oh I don’t know…*” She was clearly assessing what was most important to her. Similarly, Wayne, a 67 year old man with HF, said that he had done many things in his life, so his prognosis didn’t bother him for long, “*other than the grandkids*.”

***Ultimately living not knowing***

Despite this forward focus, the participants described this phase of their life as infused with uncertainty about the timing and the nature of their death. Bill, 83, confided, “*Well, I don’t know when I’m gonna croak* [die]*, so to speak. And nobody ever knows when they’re gonna die, so that’s not a big deal.*” Like several others, Lucy said, “*then again, you could get hit by a bus tomorrow*.” Several participants talked about significant cardiac events that involved resuscitation and cardioversion that could have, but did not, result in death. Darren, a 67 year old man with long term valve disease and HF was told by a surgeon that the surgery would “*buy me 15 years*.” He took that to mean that he would be dead in 15 years. Since that time had elapsed, he noted, “*everything that you feel, or a new symptom comes on… you kinda wanna register it. Um, is this the beginning of the end, is the question.*” Similarly, Mick, a 65 year old man, said, “*I know eventually something is gonna happen. Well, either I’m gonna have a stroke or ah…just up and die one day or…be miserable for years on end, living in a bed somewhere in a hospital… that’s the uncertainty of what’s gonna happen.*” Darren talked with a friend who had a life-threatening event and asked him if “*your life flashed in front of your eyes, any of this stuff? ‘Ah no, he said. None – none of that shit went on*.’”

 Uncertainty brought doubt – with both participants and their family members reporting wondering at holidays or events if this would be the last time that they would celebrate together. Britney, a 52 year old daughter, said that after a period of stability, she put away thoughts about “*Will this be his last birthday, his last Christmas?”*

***Need to prepare***

Although they clearly acknowledged the ‘reality’ of their impending deaths, after hearing the news about their prognosis, participants were consistent in their reactions to start planning for the end of their life in a variety of practical and psychological ways. Samantha (spouse) and Frank talked a lot about his impending death. Frank described legal matters that he had taken care of, including wills, power of attorney, titles “*and all that stuff*.” He told his wife where all the papers were and how to sell his boat. They also talked about downsizing their home; Samantha said, “*he wants to set me up for life when he’s gone.”* Lucy, a 70 year woman, began looking for homes for her pets.

“If I re-home most of them now, then I can have the controlling say over where they go…Whereas, once I’m dead, I can’t… unless I come back to haunt people. And there’s no guaranteeing I’ll be able to do that.” (Lucy)

Randy, a 60 year old man, talked about preparing his family and articulating his wishes. Mick, 65, also recognized the need to begin planning: “*I’ve got to get ready…I’m at the end of life. You know? And I gotta get a will made up and stuff like – like just think like that*”

 Despite focusing on living, Amanda talked with friends about a memorial event. “*‘I would like to have a memorial’, just like that, ‘where there was an open bar [and] … an open mic session for those that wanted to – feel they needed to say something and…’”* Afterward, she wondered whether she caused her friends discomfort and should have said nothing. Others shared their plans relating to funerals, memorial services, and cremation. Corinne, a 61 year old spouse, talked about downloading personal directive forms from the Internet for her husband who said: *“‘No I don’t. If any heroic measures there are taken, I don’t want it.’* ” This was a change from his previous perspectives on resuscitation. Andrew, a son, talked about how his mother had the “*Do Not Resuscitate instruction forms … stuck on her fridge.”* Randy talked about “*researching every kinda coffin and size and weight and shape and materials …but at some point, you just need to find a coffin.*”

Despite the urgency to plan for the end of life, some couples nevertheless found it difficult to have EOL discussions. Petra, a spouse, knew that she should be starting to collect information for an obituary: “*Dates. And where you were born. But I’m scared to bring it up, because it sounds like…we’re planning your death already? And he should know the same thing about mine, too…just don’t like talking about it, I guess.*”

Corinne said:

“I think it boils down to the [fact that he] doesn’t want to face the inevitable. And I’m getting ready to face the inevitable. So we’re on two different planes. And…if I were sitting in his position, I would probably be thinking the same thing as him.” (Corinne)

**Discussion**

This is the first in-depth study of the uncertainties of EOL during HF. There was a strong desire expressed among many of our participants for better communication with health professionals, notably physicians. Many participants expressed dissatisfaction around how the prognosis of advanced HF was communicated and general lack of communication, even when they anticipated the palliative diagnosis. Consistently, these participants desired open, frank yet compassionate, personally-connected conversations with health professionals that acknowledged that they were at EOL but did not remove hope for life before death. Given the shifts in perception as illness progresses, such conversations should be revisited regularly over time.

The reported lack of quality discussions of EOL with health professionals and the need for better communication has been found elsewhere [14,30,31]. Although HF clinical guidelines suggest EOL discussions [20,21,32], the majority of patients hospitalized with HF do not recall discussing their preferences with their physician [14]. In a recent survey regarding preference for location of death, patients with HF, even at first presentation, reported willingness to discuss EOL care [33]. These studies support the premise that people with advanced HF need and want to discuss EOL and its related issues. Although discussion of EOL is challenging, our participants’ comments indicated that they were very consistently willing to have these discussions. Their own previous experiences with death and loss made them reflect on their goals and wishes, and exploring these reflections can be a useful strategy for health care providers wishing to sensitively raise EOL goals.

Conversations about EOL are not easy and the best intended messages can be misinterpreted. Nevertheless, the concern is pervasive and the Royal College of Physicians in the United Kingdom provides guidance on the topic [34] that is consistent with the observations of our participants. Avoidance of such discussions often leads to more expensive hospital-based care that is not the preferred choice of the person with HF [5].

Barriers to this communication still exist in cardiac care settings. The disease course of HF is often unpredictable, making it difficult to identify a specific time point to introduce palliative care to HF management. The enduring tendency to focus exclusively on treatment and cure is concerning [34]. Kindtworth et al. [35] found that communication with physicians caring for older people with HF predominantly focuses on curative treatment rather than self-management of the disease, dealing with emergency situations and EOL issues.

Effective training and use of palliative approaches should enhance the quality of communication at the EOL [6]. While there is wide variability in availability and quality of training programs related to HF EOL care, there is evidence to suggest that knowledge, attitudes and preparation for practice can be improved [36].

A significant observation was that the physician was the only health professional role mentioned during data collection - despite availability of other providers such as registered nurses and nurse practitioners in these HF clinics. In part, this may be because it is traditional for physicians to deliver news about diagnosis and prognosis. Our hierarchical North American health system where priority is given to physician perspectives may also be contributing to this situation. In other studies, it has been reported that nurses working with people with HF are often reluctant to discuss prognosis also considering it to be the physician’s role [15]. Nevertheless, nurses have an important role to play in enhancing EOL care.

Training on palliative care approaches for cardiac care professionals should be developed and evaluated. An intentional palliative care approach involving all members of the team could foster improved communication among patients, family members and the multidisciplinary health team members [6]. Such approaches facilitate advanced care planning, and support improved quality of life/EOL experiences in patients and family caregivers [6]. The Palliative advanced home caRE and heart FailurE caRe (PREFER) study [37] provides an example of person‐centred care combined with active HF and palliative care at home offered people with severe HF improved quality of life and reduced morbidity. The PREFER person-centred care intervention offered more frequent nurse home visits compared with the usual care group, resulting in improved quality of life, self-efficacy and reduced symptom burden.

Although the same themes emerged from the data of people with HF and their family members, at times, there were differences in perspectives within the dyad. These seemed to relate to varying perceptions of quality of life of the person with the illness and wishes for EOL care. These differences are unsurprising. In the quality of life literature, differences in perceptions between patients and family members, and patients and physicians are common [38, 39]. The need for patient- and family-centred care and patient-oriented research has never been stronger. Unlike most interventions to promote self-management of HF [40], design of these interventions rarely incorporated patient and family perspectives and preferences for EOL care. Additional research relating to the impact of EOL care in HF on family caregivers is warranted.

This study may be limited because people who decided not to participate may feel less comfortable talking about EOL and may have different perceptions than our participants. Our sample included only patients and family whose health professionals recommended participation. Four participants did not identify a family member to participate, so we were unable to fully understand the experience of the dyads.

In summary, the findings from this narrative inquiry illuminate perceptions about death and dying with advanced HF for people with the illness and their family members. Key storylines evident in the data included: *prognosis messages received from physicians; whenever I die, I die; loss isn’t new to me but….; carrying on amidst the fragility of life; ultimately living not knowing; and preparing.* These themes highlight opportunities to better understand perceptions of people with advanced HF and their family members as death approaches.

**IMPLICATIONS FOR PRACTICE**

* Acknowledge imminent end of life but do not remove hope
* Communicate frankly, sensitively, not bluntly
* Discuss other losses to open into end of life topics
* Conversations about end of life should occur multiple times
* People want to carry on until they become a burden

**CONFLICTS OF INTEREST:** none declared

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**Table 1**: Sample Interview Questions

**Sample questions for person with heart failure**

Tell me about what it is like to live with heart failure (HF).

How have you experienced uncertainty in living with HF?

How do you describe/talk about your illness?

Tell me about the care you have received from family members and healthcare providers as you have lived with HF.

How have your experiences changed as your illness has become more serious?

Is there a time that stands out for you in coming to face living with HF? Please describe that time and its impact in your life.

In living with HF, how have your thoughts on facing the end of your life changed (if at all)?

What do you know now that you didn’t know before you developed HF?

What is important to you now?

Can you tell me about times since your diagnosis when you were struggling with the big questions of life? What questions came up for you?

Can you please tell me about any aspects of living with HF that are challenging to speak about?

What support (healthcare provider or care giver support) has made a difference for you in living with your illness?

**Sample questions for family members**:

Tell me about what it’s like caring for your family member diagnosed with HF.

How have your experiences of caring for your family member changed over time?

Tell me about the uncertainties you face in caring for your family member.

How have your experiences changed as your family member’s illness has become more serious?

Is there a time that stands out for you in coming to face the impact of your family member living with this illness? Please describe that time and its impact in your life.

In caring for your family member how have your thoughts on facing end of your life changed (if at all)?

What do you know now that you didn’t know before you began to care for your family member?

What is important to you now?

Can you tell me about times since your family member was diagnosed when you were struggling with the big questions of life? What questions came up for you?

Can you please tell me about any aspects of caring for your family member that are challenging to speak about?

What support (healthcare provider or community support) has made a difference for you in caring for your family member?