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Achieving Medical Stability: Wives' Experiences With Heart Failure

Abstract

The incidence of heart failure continues to rise as innovative treatments are developed. Despite life-prolonging interventions, morbidity and mortality in patients younger than 65 remain high. Few studies have focused on this younger cohort and/or their family caregivers as they navigate the complex illness trajectories manifested in heart failure. Instrumental case studies were employed to present exemplars for each of the five identified heart failure trajectories. Culling data from a longitudinal study of female spousal caregivers, each case study represents a wife's discussion of caring for a husband (<65 years) in response to the husband's changing heart failure trajectory. The goal of medical stability and the notion of uncertainty permeate throughout the case studies. Suggestions for supporting these wives are presented.

Keywords: illness trajectories, heart failure, spousal caregivers, instrumental case studies

Approximately 5.8 million people in the United States are living with heart failure (HF), with 670,000 new cases added each year (Lloyd-Jones et al., 2010). It is predicted that the incidence and prevalence of HF will continue to increase as the population ages and innovative treatments for cardiac disease improve survival rates. The advances in treatment of cardiovascular disease, such as control of hypertension and interventions for myocardial infarction, are key factors in reducing mortality from heart attacks, yet with this decrease in mortality comes an increased risk of developing HF later in life (Stuart, 2007). Along with debilitating symptoms such as shortness of breath, fatigue, and pain, patients diagnosed with HF bear the burden of high mortality rates (Fonarow, 2006; one in five people die within a year of diagnosis; Lloyd-Jones et al., 2010) and have a risk for sudden death that is six to nine times the rate of the general population.

Despite the fact that the prevalence of HF dramatically increases with age and that thus almost 15% of the population older than 80 lives with HF (AHA 2010), as many as 13% of HF patients are younger than 65 years of age (Lloyd-Jones et al., 2010). In the <65 age-group, 70% of women and 80% of men will die within 8 years of diagnosis (AHA, 2010). The uncertainty of the course of the HF trajectory is affected by the complexities of managing an intricate medication routine, maintaining a strict dietary regimen, and dealing with symptoms such as fatigue, anxiety, depression, dyspnea, and moodiness (Davidson, Paull, Rees, Daly, Cockburn, 2005; Horne & Payne, 2004; Quaglietti, Atwood, Ackerman, & Froelicher, 2000). The demands associated with living with HF are often shared by an informal family caregiver, usually the spouse, and impose both physical and emotional demands on the caregiver (Harkness & Tranmer, 2007). Researchers have found that younger caregivers of HF patients report poor mental health, poor perceptions of control, and greater perceived difficulty with caregiving tasks than their older counterparts (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006). Few studies have focused exclusively on the experience of people younger than 65 living with HF, thus missing the unique perspectives of these patients and their caregiving spouses. In addition, studies have not investigated variations of the experience of living with or caring for a person with HF in relation to the different courses or trajectories manifested in HF so that supportive interventions can be tailored to this group of patents and their caregivers. Therefore, the purpose of this article is to illustrate the experience of living with HF in patients younger than 65 as described from the perspective of their wives. Five case studies are presented, each illustrating a unique HF illness trajectory that the husband (<65 years of age) traversed over a period of 12 to 18 months to show the differences and similarities of the experiences.

Background

Heart Failure Illness Trajectories

Variations in the terminal illness or death trajectories were initially proposed in terms of two properties, duration of the terminal trajectory and shape of the trajectory (Glaser & Strauss, 1965). From this conceptualization, four common death trajectories have been described, sudden or unexpected death, steady progressive decline with a terminal phase (e.g., terminal cancer), slow decline punctuated with crises followed by “sudden death” (e.g., organ failure), and a slow decline leading to death (e.g., frailty; Field & Cassel, 1997; Murray, Kendall, Boyd, & Sheikh, 2005).

HF does not easily fit into one of these death trajectories because of the unpredictable course of the disease. In contrast to a fairly predictable terminal illness trajectory, such as advanced lung cancer, there are multiple illness trajectories that are manifested in people with HF, with no single trajectory capturing the totality of the experience (Goodlin et al., 2004; Hupcey, Penrod, Fenstermacher, & Boehmer, 2008). Historically, the “typical” HF illness trajectory has been characterized as a slow steady decline in functional status with increasing severity and frequency of symptoms over time, punctuated by periods of unpredictable exacerbation from which patients may or may not recover (Goodlin et al., 2004; Gott et al., 2007; Meier, 2008; Murray et al., 2002; Stuart, 2007). Because of the complex and unpredictable nature of HF, others have broadened these conceptualizations to include the variable course of HF (Goodlin, 2005; Goodlin et al., 2004). However, the true unpredictable nature of the end-of-life course of HF was only recently mapped out by Gott et al. (2007). They followed 27 patients with HF until death and found five different trajectories based on the patient’s physical limitation over the course of up to 24 months prior to death. The death trajectories included ones that were similar to frailty, terminal cancer, and typical HF but also included one showing an improvement before death and one with fluctuations but without a downward decline before death.

Hupcey et al. (2008) followed 46 patients living with (not necessarily dying from) HF over the course of 12 to 18 months. They found that, in addition to the typical illness trajectory of a slow insidious decline with or without crises that may ultimately lead to an “unexpected” death, there were four other prominent HF trajectories. These trajectories included sudden death from HF, living with HF while awaiting a heart transplant, living with HF following placement of a device or change in medical management leading to medical stability, and the slow decline HF trajectory with the introduction of hospice care (thus death not unexpected).

Heart Failure in Adults Younger Than 65

The surgical and medical interventions that save patients from dying acutely of heart disease have contributed to a cohort of younger patients with diseased hearts who are living with HF (Kirkpatrick & Kim, 2006). For instance, with the use of destination therapy (left ventricular device), survival rates have been shown to increase with an overall reduction in mortality of 66% and a 2-year survival rate of 77% (Long et al., 2008). Such outcomes have influenced the traditional trajectory of HF, particularly for patients younger than 65 who are typically candidates for these high-risk interventions and new therapies. Therefore, as new treatments provide hope for a longer life, HF patients younger than 65 and their spousal caregivers may have experiences that differ from the elderly patient.

The experience of living with the debilitating illness of HF for younger patients and their spouses has been described as different from those who are older, with younger patients reporting a worse health-related quality of life than older patients (Zambroski, Moser, Bhat, & Ziegler, 2005). For younger patients, functional impairment also leads to a greater incidence of depressive symptoms (Vollman, LaMontagne, & Hepworth, 2007). In addition, the inability to work because of HF, often increases the financial strain as fewer financial resources are available (Pattenden, Roberts, & Lewin, 2007). When faced with the physical restrictions of HF, younger patients report the emotional strain of feelings of loss, role limitations, and feeling as though they are a burden (Callahan, 2003). Despite the increasing incidence of HF and the potential for high caregiving demands, few studies have comprehensively articulated the physical and psychological impact of the subjective experience of family caregiving in HF, particularly with younger caregivers (Molloy, Johnston, & Witham, 2005). This article will address this void by illuminating the perspectives of wives over a 12- to 18-month course to describe the experience of caring for a husband (<65) with HF.

MethodInstrumental case studies were employed to present exemplar cases, from the perspective of wives, for each of the five HF illness trajectories identified by Hupcey et al. (2008). Stake (1995) described the method of instrumental case study as the presentation of cases bound by a specific experience. Each case represents a wife’s discussion of caring for a husband with HF in response to the husband’s changing health situation as he traversed one of the five HF illness trajectories. According to Stake, the use of instrumental case studies allows researchers to deeply examine cases that provide insight and facilitate understanding of issues of interest to understand a facet of the case better. In this article, the phenomenon that bounds the cases is caring for a husband with HF and the changing needs in response to the husband’s specific HF trajectory. Each case presented in this article was chosen as an exemplar case from the data set because that participant most clearly articulated living through a particular HF trajectory.

Data Collection

Sample and setting

Data for this study were part of a longitudinal investigation of the palliative care needs of female spousal caregivers of male HF patients <65 (NIH/NINR; 1R15NR009976). This study sought to identify the need for palliative care services for patients with HF and their family caregivers. The wives were asked to participate during their husband’s hospitalization for an acute exacerbation (or new diagnosis of HF) or during a follow-up clinic visit after an exacerbation. All patients were followed at a large regional HF center that serves patients within a 100-mile radius of the institution. The only exclusion criteria for the study were a concurrent diagnosis of HF, non–English speaking, and evidence of psychiatric disorder or cognitive impairment that preclude insightful reflection. During recruitment of subjects, only one wife declined participation, citing that she was also caring for her mother and could not spare the time. Once informed written consent was received, in-depth longitudinal interviews were begun. The initial interviews were in-person with subsequent monthly interviews in-person or over the phone. Participants were interviewed regularly for 12 to 18 months (with the goal of at least 12 interviews per participant or until the husband died). Three husbands died during the study. These participants completed 7 to 12 scheduled interviews and all completed a postdeath follow-up interview. All other participants finished the study, with a total of 24 participants completing the 12 interviews. The interviews focused on the experience of caregiving and the changing needs over the course of the 12 to 18 months. During each interview, participants were asked to describe their husband's condition, their caregiving experiences (and changes in the experience), support networks, thoughts about the future, financial concerns, and specific unmet needs related to caring for a husband with HF.

Data Analysis

During data analysis, the HF trajectory was mapped out based on the wife's description of her husband's HF status at each interview. Each of the participants' husbands fit into one of the five unique trajectories, although the particular trajectory may have changed through the course of the study (five husbands were transplanted during the course of the study, so moved from the trajectory of awaiting heart transplant to posttransplant, therefore were no longer following a HF trajectory). An exemplar case from each trajectory that best described both unique and similar experiences of wives living through that trajectory was chosen.

Results

Sample

Twenty-six wives whose husbands (age <65) were being followed at a major HF center were interviewed. All of the couples, except one, were Caucasian. The mean age of the wives in this study was 55.7 years (range = 27-68, *SD* = 8), and the mean age of the husbands was 55.8 years (range = 31-64, *SD* = 7.5). Patients lived between 15 minutes and 3 hours drive time from the HF center. Many of the patients were cared for by a cardiologist in their hometown, coming to the HF center for periodic follow-up or further diagnostic testing. Following completion of the longitudinal set of interviews, the full data set for each female spousal caregiver was analyzed to determine the present HF illness trajectory of the husband at the time of the wife's final interview. These were sudden death (3); slow insidious decline with or without acute exacerbations (5); medical stability following an intervention, placement of a device, or change in medical management (12); slow decline to hospice (1); and heart transplant (5). At completion of the study, there were no patients remaining on the transplant list.

Five exemplar case studies are presented, each illustrating the experience of the wives in relationship to one of the five unique HF trajectories identified by Hupcey et al. (2008). Characteristics of each trajectory are described prior to the exemplar. A major theme of *seeking* *medical stability* permeated throughout all experiences. All of the wives expressed a hope for medical stability as a goal. For example, “I know he isn’t going to get better, but I hope he doesn’t get any worse.” The identity of the subjects has been protected by removing or changing certain descriptors that do not change the meaning of the case studies.

Case Study Exemplars

Case 1: The sudden death heart failure trajectory: Unexpected death. The sudden death trajectory is characterized by a death that is unanticipated by the caregiver. Rather than the slow decline of frailty where death may be expected, this sudden death may follow a series of exacerbations of HF where the patient always recovered. Hence, wives come to expect medical stability after every hospitalization and are unprepared for the death of their spouse. The following case study is an example of such an experience. Mrs. J’s husband had his first heart attack 13 years ago at the age of 48. Now on disability for 2 years, Mrs. J’s husband has had repeated hospitalizations to treat fluid retention, as frequently as every 2 weeks. Her frustration with the frequency of hospitalizations is evident in the following quotes from her interviews:

> He has been in and out of the hospital every two weeks … and I know it’s very frustrating for him … I do feel bad because I can see him gradually deteriorating in front of my eyes. And it breaks my heart because I know what he was, and I know what he was capable of doing. And now, I know it is at the point where he just can’t do it anymore.

One month later, Mrs. J was interviewed again. At this point, Mrs. J’s husband was home and back to what she perceived as “normal.” Because he had not been hospitalized within the last month, she described the recovery as “unbelievable.”

> Well, he wasn’t doing well at all … but for some miracle, I don’t know what it is, he’s improved so much. It’s unbelievable. He’s really feeling so much better. I can’t explain it. It’s just unbelievable, the turnaround he made …

But only 5 months later, Mrs. J’s husband died suddenly during what she perceived would be just another routine hospitalization to treat his fluid retention and shortness of breath.

> I know my husband hasn’t been well for the past year. You know how many times he was in and out of the hospital …, but still in all, he always came through. He’d come around. He was doing good. I could see my husband was really slowing down a lot, but … I didn’t think he was dying. No indication was ever given to me. I knew he was sick. He had a lot of things against him, but I never expected him to pass away. Never.

Mrs. J was shocked by her husband’s death from HF, despite his frequent exacerbations and acute hospitalizations over the past year. She interpreted the time periods in between hospitalizations as stability, “he was doing good.” She described his exacerbations as “frustrating” and “sad,” yet “he always got better,” indicating her expectations of medical stability in between the exacerbations. After the death of her husband, as Mrs. J reflected back on her experience, she could recognize the slow downward decline that she was unable to realize while living through it. Nonetheless, her husband’s death came unexpectedly from her perspective.

Case 2: Living with a slow decline from heart failure: Increasing responsibilities of care

The trajectory labeled as living with a slow decline from HF describes HF patients who are managed with medications and/or with the use of surgical interventions such as pacemakers/defibrillators to treat the symptoms of HF but are not yet or maybe never will be a heart transplant candidate. Patients in this trajectory have long periods of stability punctuated with occasional exacerbations and a notable slow decline in their ability to tolerate physical activity. The second case study describes the experience of a young married couple with a young child, living with HF as a result of the husband’s congenital heart defect. The experiences of this young family over the course of a year revealed a trajectory of a slow decline over time with periodic crises. At 27, Mrs. R is well educated, works outside the home, and was the youngest of the wives in the study. Her husband, now in his early 30s, was diagnosed with hypertrophic cardiomyopathy as a young child. Despite the fact that Mr. R still holds a full-time job where he works at a desk, he has experienced a slow decline in his activity level associated with his worsening HF. Mrs. R describes what she has experienced during the first years of their marriage as she noted the decline in her husband’s activity level.

This has been a huge life adjustment for me because if he wouldn’t have this condition, I would have him out hiking, I would have him out canoeing, I would be doing all sorts of stuff like that with him. That has been a big adjustment for what I envisioned our family to be like.

Even in the times of medical stability, Mrs. R noted the slow decline in her husband’s capacity for physical activity. When asked about how this limited physical activity has affected their roles at home, Mrs. R replied,

It has changed a lot … for my husband, it’s hard knowing that he can’t pick up the little baby carrier and walk him in the house for me. Like I’m the wife, but I still have to do the shoveling and the manual labor.

Mrs. R credits the physical activity limitations as the stimulus for her husband’s depression and sadness.

He has more depression over the past 2 years, definitely. Maybe not even depression, but simply sadness, especially when the baby arrived because, well the increased responsibility and he wants to be there for him when he grows up. Yeah, the happy-go-lucky personality that he had when I met him is not the same. Even on his good days he’s a different person.

Like many couples living with HF, Mr. and Mrs. R feel the financial burden of the illness.

We don’t go out to eat, because we buy pills. We’ve been hit by quite a few medical bills these past 2 months.

This case is a poignant reminder that the experience of HF is especially disruptive for young couples who are just starting out in life together. Mrs. R is also shouldering the responsibilities of the physical aspects of childcare. Along with these tasks, this young wife has the emotional burden of seeing her husband’s own personal struggles with depression and physical limitations. The demands on the wife as the informal caregiver escalate in tandem with every decline in her husband’s status. Even in times of medical stability the care responsibilities remain, with relief never in sight.

Case 3: Living with heart failure while awaiting a heart transplant: Fearful anticipation

Once a HF patient is placed on the heart transplant list, the experience from the caregiver’s perspective takes on new meaning, as illustrated by the following case. Patients and wives in this trajectory experience planned hospitalizations, which often place an additional financial burden on the family. Although there is anticipation that life after the heart transplant will be better, there is also a fearful anticipation about going through the experience. The third case study describes the experience of Mrs. Y as her husband awaits a heart transplant. Mrs. Y is a 60-year-old woman, newly retired from a job from which she still receives health insurance for her husband and herself. Although she and Mr. Y have been together for many years, they have only been married for two years. Her husband, now 58, was diagnosed with HF 5 years ago and had an internal cardiac defibrillator placed. At that point he was no longer able to work, and he was forced to sell his business. Two years later, he had an Acorn device placed, which Mrs. Y describes as a mesh support around the heart.

The couple lives in an extremely rural area 3 hours from the HF center. Two years ago, Mrs. Y’s husband became very ill and was taken to the HF center by ambulance. Mrs. Y recounted the stress caused by that exacerbation, both in terms of financial strain to pay for unexpected and unreimbursed costs of ambulance transport and the distance and cost to travel 3 hours to the hospital to be with her husband. Mrs. Y describes her understanding of the treatment options for her husband after a serious hospitalization for complications from both HF and diabetes.

It’s my understanding that the only other thing would be like a heart transplant. So we’re hoping that we don’t ever have to do that, but you never know. He just doesn’t feel good. I don’t expect him to ever get better, but I’d like to see it stay steady. I’d be happy with it just never getting worse.

Despite Mrs. Y’s hopes for medical stability, 5 months later, her husband’s condition continued to deteriorate.

So they ran a whole bunch of tests and his cardiologist indicated that they were going to do all the pretests for a heart transplant. That just kind of blew us away. I’m just scared to death. I think he is too.

Two months later, Mrs. Y’s husband was placed on the heart transplant list, and he began a series of monthly hospital admissions, each lasting a week, in preparation for receiving a heart. With each of these hospitalizations, Mrs. Y stayed at a nearby motel so she could be with her husband.

The financial and emotional strain of the experience was evident in follow-up conversations with Mrs. Y.

Major overwhelmed. You know it’s still kind of overwhelming, but now knowing that we’ll be going down there once a month, I think we’ve had a chance to come to terms in our mind about the heart transplant, and while it’s scary, we’re both looking forward to it, so hopefully it will give him a new life where he can function a little bit better and feel better …

Even with insurance coverage, there are still many out-of-pocket expenses, causing considerable financial strain.

I’m staying at the (Motel) and they tell me that’s like the cheapest place that you can stay, but we’re spending several hundred dollars a month for lodging and for me to eat, and I don’t eat a lot. Well, that’s a lot of money out of your paycheck when you’re retired.

Although she never spoke about her fear that he might die, she tearfully revealed her sense of urgency to be with him.

I would not want him to go into the operating room getting that heart and me not being here to see him going. So he knows that I’m here. Cause I know that would mean a lot to him. You know if I wasn’t here and they took him in that operating room and he didn’t see me before he went … That would bother both of us.

Mrs. Y’s experience reveals the financial impact and the emotional toll associated with the experience of living with HF when couples live a great distance from the treatment center, especially during the exacerbations that require hospitalization. This case demonstrates the wife’s vigilance that is heightened even during times of medical stability while waiting for a heart transplant. More important, the case details the transitions of the wife’s experience in concert with every exacerbation of her husband’s illness.

Case 4: Living with heart failure following placement of a device leading to medical stability: Pervasive uncertainty

Case 4 illustrates the experience of living with HF, with a left ventricular assist device (LVAD) as destination therapy as the last option, but with long-term medical stability following its implantation. This trajectory is characterized by a slow steady decline that is seemingly reversed after the implantation of a destination therapy device. On receiving the device, patients who were once severely restricted in their physical activities are able to be more physically active. However, little data exist to predict the length of time a device such as the LVAD will be effective. Therefore, there is also a pervasive uncertainty that characterizes the experience, as illustrated in the following case study. Mr. E, aged 64, has a greater than 25-year history of heart disease, with multiple bypass surgeries that resulted in him becoming disabled at the age of 50. Mrs. E, now at age 61, was the sole family support for years until she also became disabled. The financial strain of being on disability, along with the multiple hospitalizations for Mr. E, resulted in the family selling their small home and moving to a tiny apartment, only to have to move a second time within a year to find cheaper rent.

We went from paying $250 per month because we owned the trailer to $500 per month in the apartment. Now we have 60 days to get out of here. They sold the building. So we went from paying $250 to over $500 in less than a year, which wouldn’t be bad except our medication bills, run $2,000 to $3,000 per month.

Mrs. E’s first interview was approximately 3 months after her husband had the LVAD placement. At this point she explains her continued concern about the machine, infection around the drivelines, bleeding, loss of electricity, and the inability to quickly be transferred to the HF center if there was a problem with the LVAD.

And I still don’t know. They’re trying to make it black and white—well we’re always in that gray area … the first week we were home and the power went out, I was dialing on a cell phone in the dark. This is a big worry for me, neither one of us really know what to do when that red light goes off, other than call 911.

Over the next few months, she was also stressed about the numerous unpaid hospital bills and the continual cost of expensive medications and hospital visits.

So even though we have a big whopping income of $2,500 a month on a disability level—the medication bill and the doctor bills are out of this world. I guess one of the biggest ways it has affected us is we lost $30,000 of our retirement money that went in to health premiums till we got the Medicare.

As she spent her time worrying, Mr. E, who was virtually homebound prior to the LVAD, was now driving and visiting with friends. He seemed to look at this time as borrowed time, and he was going to enjoy himself. During this time she was very frustrated, and she spoke about their relationship failing and that no one, including both family and health care providers, was there to support her as the main informal caregiver.

So basically he said he wanted to walk and breathe and that’s exactly what the pump is doing, but he seems to think that he’s totally better now cause he has the pump and he’s doing good … But basically he is living on borrowed time, so he’s out enjoying himself and not taking care of himself or worrying about bills or about me. I work all day taking care of him. So basically I’m not a wife, I am just a nurse, a secretary … I guess maybe spouses need a little more help along the way, much more than I realized because it’s taken its toll on me.

During the final interview, as she reflected about the past and future, Mrs. E felt that the health care team was only focusing on the here and now and the fact that he was medically stable with the LVAD (he was 18 months post-LVAD placement at this point). She is worried about the future, and she feels that the doctors are only looking at the present.

Dr. (heart failure) more or less tells him that he is doing well on this, so nothing to worry about.

Mrs. E’s experience illustrates a variety of fears, financial concerns, and generalized uncertainty following the decision to pursue destination therapy. Once Mr. E was home, she became more than the coprovider of care, she was the sole caregiver for both Mr. E and his machine. She became the “expert” at LVAD care and yet was fearful of the consequences of having the LVAD. For Mrs. E, the times of medical stability were fraught with uncertainty about the future.

Case 5: The slow decline heart failure trajectory with hospice care: Relief and sadness

Although only one of the patients in this study was referred to hospice care, it is nonetheless important to describe as a unique trajectory because the experience is very different from the patients and caregivers who are seeking active treatment for HF, as death is anticipated. Hospice provides a welcome relief from the duties previously shouldered by the caregiver. Case 5 describes the experience of Mrs. G as her husband becomes progressively worse with advanced HF. Following the decision to forego further treatment for his HF, Mr. G is placed on hospice. Mrs. G. is a 54-year-old woman who earns only minimum wages. When her husband, now 61, became disabled, the couple could no longer afford their mortgage, so they sold their home and moved into a small mobile home. Several years ago, Mrs. G’s husband started to decline, requiring frequent hospitalizations for exacerbation of his HF symptoms. Mrs. G was first interviewed while her husband was in the hospital during a serious exacerbation where he nearly died. During that interview and in subsequent interviews, she repeatedly talked about the financial strain of trying to make ends meet while caring for her husband. Every time Mrs. G’s husband was hospitalized, she had to take time off from work, which meant she lost wages and she struggled to pay their bills.

I mean, we just keep our heads above water just enough, you know. That’s it.

After the decision to place her husband in hospice care, Mrs. G felt relief that she would have help. She would not have to miss work for doctor’s appointments and hospitalizations, which meant less financial strain.

The doctors say there’s nothing more they can do for him. He’s not gonna get any better than what he is. I don’t have to worry about him going for blood work and stuff, because they’ll do it for us. They (hospice nurses) make sure he has his medicine. I won’t be sitting at work worrying so much. It’s a relief.

After 2 months on hospice care, Mrs. G is asked how she is doing since the transition to hospice.

Yeah, all I do is day by day. I don’t really know how to explain it because I just deal with it. I guess I have broad shoulders.

In Mrs. G’s case, the transition to hospice care was seen as a welcome relief from some of the caregiver burden that she had been experiencing, especially as the severity of her husband’s condition escalated, yet a period of sadness, as she awaited his death. Missed time from work to take her husband to the hospital and to appointments meant less take-home pay and an increased strain on the finances. Mrs. G’s way of coping with the stress of her husband’s illness was to take things “day by day”. For Mrs. G, hospice brought a period of medical stability that was mixed with a feeling of relief as well as new concerns and uncertainty about the future.

Discussion

The five instrumental case studies presented in this article illustrate the experience of living with HF from wives' perspectives, in relationship to their husbands' HF trajectories. As the couples experienced a change or an exacerbation in the husbands' condition, the wives looked ahead, seeking the next period of *medical stability*. For every change in the husband's HF trajectory, the wives' experiences were affected, resulting in an emotive, physical, or psychological response that was rarely addressed by health care providers. Yet, even without support, the wives responded by providing care in synchrony to the ebb and flow of the husband's experience, through the times of stability and through the exacerbations. As one wife so aptly put it, "When he is having a good day, I am having a good day. When he isn't so good, neither am I."

In the face of the physical limitations, frequent hospitalizations, and the high risk of mortality, almost 750,000 people under the age of 65 are living with the diagnosis of HF, All too frequently, HF patients have their level of health quantified by clinical markers such as lab values and ejection fractions without consideration of the emotional stressors or prognostic indicators that highlight the course of the illness (Callahan, 2003). Thus, wives, such as presented in Case Study 1 (*unexpected death*), do not anticipate beyond the periods of *medical stability* and these indicators. For those living with HF who are younger than 65, the experience is different from an elderly HF patient-caregiver dyad, mainly because of the norms that characterize this season of life. For example, there are the added emotional factors of changing roles as wives younger than 65 often still work a full-time job or need to start working in addition to assuming the additional caregiving responsibilities for a husband with HF who was forced to take early retirement or disability. In our sample, the diagnosis of HF was accompanied by the need for early retirement or disability in all but one case. This event was frequently followed by a cascade of financial strains, including paying for the high cost of medications, downsizing a home, and often missed work, thus loss of pay, for the wife. In addition, these wives reported concerns about finances not only related to less income but also to the added expense of travelling to doctor appointments (e.g., Case Study 3). These identified concerns were amplified in those living in poverty and those with lack of social support (e.g., Case Study 5).

This article adds to what other researchers have found in terms of the caregiver experience by identifying unique experiences based on the care recipient's HF illness trajectory. For example, in response to caring for husbands with an LVAD (e.g., Case Study 4), wives have reported that taking on this added work was overwhelming and stressful (Casida, 2005). As the household tasks and responsibility for managing the patient's care at home escalates, the mental health and emotional well-being of the caregiver are negatively affected (Bakas et al., 2006). As the husbands' illness trajectories changed, so were the wives' experiences responsive to the nature and course of the illness. Previous research has identified that patients and family members need support as they are going through the exacerbations or disruptions that punctuate the HF experience (Luttik, Blaauwbroek, Dijker, & Jaarsma, 2007; Mahoney, 2001). Additionally, Luttik et al. (2007) report the need for couples to regain balance after a hospitalization or an acute phase of HF. In the case studies reported here, the quest for medical stability emerged as a primary focus, especially after an exacerbation. The case studies also illustrate that, even in times of medical stability, couples living with HF need significant support. For example, even in two-income families, the cost of medications for the medical management of HF is often beyond the couple’s financial means (e.g., Case Study 2).

It is during the periods of medical stability, or the “good days,” that the work of the spouse often goes unrecognized by health care providers. As seen in the case studies, support from health care providers was not mentioned. Yet it has been shown that caregivers need support and information about managing patients’ symptoms to alleviate the uncertainty about decision making in the home setting (Given, Sherwood, & Given, 2008). Sebern and Riegel (2008) also have suggested that involving both members of the spousal dyad in the care of persons with HF improves the patients’ self-care. Not including a spouse in communication with health care providers and the patient results in feelings of isolation and less involvement in the care of the patients at home (Martensson, Dracup, & Fridlund, 2001). Because supportive relationships have been shown to improve outcomes for HF patients (Sebern & Riegel, 2008), providing information aimed at improving caregiver engagement may actually reduce the number of hospitalizations and increase the time period between exacerbations for HF patients.

Implications for Practice

Health care professionals who care for HF patients could significantly affect the experience for both the wife and the husband living with HF by giving the couple a realistic and honest appraisal associated with the diagnosis of HF. Although no one has the prognostic capability to pinpoint every expected turn in the trajectory, anticipatory guidance about the dynamic nature of the trajectory, along with the impact on finances, emotional burden, dealing with depression, and end-of-life planning would be of enormous benefit to the wives caring for husbands with HF. Results of this study demonstrate that the needs of couples, especially the needs of the wife as a coprovider of care, require more than just brief contact with the health care provider. The case studies illustrate that whenever there is a change in the husband’s HF trajectory, such as an acute hospitalization or introduction of a new intervention, the needs of the wife escalate in tandem with the husband’s experience, but are manifested in different ways. The needs of the wives are just as acute as the medical needs of their husbands and must be anticipated and addressed by health care providers.

Future Research

There is a need for further qualitative research to provide physicians and nurses with insight into the experience of living with a chronic illness, such as HF, in patients who are younger than 65. New trajectories for conceptualizing the path of HF must be considered, especially for those HF patients who are in midlife, with life-prolonging treatment options increasingly available. The traditional trajectory of HF illustrating a slow decline typically manifested in the frail elderly patient is not adequate for describing or prognosticating the experience for those younger than 65 years. New models for introducing palliative care according to the unique needs of HF patients must be considered (Hupcey, Penrod, & Fenstermacher, 2009).

One limitation of this study is that participants were predominately Caucasian, and the husbands were cared for at a major HF center. Future qualitatively designed studies involving couples from various ethnic and racial back-grounds living with HF would add rich and meaningful data to help provide culturally sensitive care. Likewise, the experience of couples living in rural areas without access to life-prolonging technology is not well described in the literature. As the number of younger people younger than 65 living with chronic illness, such as HF, continues to increase, nurses are well positioned to make a difference in the lives of patients and their caregivers as researchers, educators, and clinicians.

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Footnotes

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