# Naive Expectations to Resignation: A Comparison of Life Descriptions of Newly Diagnosed Versus Chronic Persons Living With Stage D HF

Journal of Patient Experience 2018, Vol. 5(3) 219-224 © The Author(s) 2018 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/2374373517750412 journals.sagepub.com/home/jpx SAGE

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## Abstract

**Purpose:** This study examined life descriptions of persons with stage D heart failure (HF) comparing those newly diagnosed to those with chronic HF. **Methods:** A secondary analysis of interviews from 75 participants followed in a longitudinal study of persons with stage D HF was thematically analyzed. There were 24 participants who were recently diagnosed with stage D HF (less than 2 years) and 51 participants with HF longer than 2 years. **Results:** Both groups shared life descriptions along a continuum, where recently diagnosed participants described naive expectations with hope for improvement, while the chronic group appeared resigned to their fate and the reality of the limitations of living with HF. Four themes illustrated differences between the groups: outlook on life, activity adjustments, understanding of HF, and mood. **Conclusions:** Although persons with stage D HF share the same life descriptions, they have differing perspectives of life with HF. Findings from this study can help health-care providers tailor interventions based on the length of time from diagnosis.

#### **Keywords**

advanced heart failure, life descriptions, qualitative research

Heart failure (HF) is the most common primary diagnosis in hospitalized adults over the age of 65 (1). Currently, there are almost 6 million individuals living with HF in the United States, with over 23 million individuals worldwide, and it is predicted that this number will continue to grow (2,3). With treatment advances and rapidly evolving technology, survival for patients with acute myocardial infarctions has greatly improved, creating a group of individuals at high risk of developing HF (4).

Heart failure is a progressive, incurable disease with a variety of debilitating symptoms that negatively impact the lives of those living with the illness (2). Symptoms of HF include shortness of breath, cough, weight gain, nausea, fatigue, edema, and pain. These burdensome symptoms are generally managed through medication optimization and lifestyle modifications. Unfortunately, even with effective management, HF and its associated symptoms will progress to an end stage of disease. End-stage HF is classified by the American Heart Association as stage D. In stage D, individuals with HF experience symptoms at rest, including breathlessness, fatigue, and activity intolerance, are refractory to optimal medical management (5). The characteristic, progressive weakening of the heart muscle in HF often results in persons living with HF losing their ability to work or perform activities of daily living (6–8). However, little is known about the experiences of these individuals as they live with stage D HF. Recognition of the impact of these

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progressive changes by health-care providers is vital to the provision of person-centered HF management.

In addition to living with the high symptom burden associated with stage D HF, these individuals must also manage a life-limiting illness on a day-to-day basis and engage in appropriate self-care. A recent integrative review highlighted the challenges of persons living with HF as they attempted to incorporate their experiences of living with HF into their day-to-day lives (9). For persons with stage D HF to effectively manage their condition, it is critical to understand their perceptions of their illness and how they view themselves in the context of this experience. These perceptions could impact how a person living with HF assumes the responsibility of effectively managing their illness. Several qualitative studies have shown that persons with HF often do not understand the nature or seriousness of their condition (9,10). Additionally, misperceptions of disease severity have been reported to have a negative impact on a person's self-management strategies (11). What it is not clear from the current evidence is how the experience of living with stage D HF changes over time or whether the experience is different based on the length of time a person has been living with HF.

Numerous studies have examined the needs of persons living with HF and described the general experience of living with HF; however, changes in life descriptions of HF over time have not been well investigated. For the purpose of this article, life descriptions are defined as the perceptions of living with stage D HF from the perspective of persons living with the illness. Examining the life descriptions of persons living with stage D HF can provide insight into how perceptions may change over time and may help inform individualized, person-centered interventions for this population. Therefore, the purpose of this study was to gain an understanding of the life descriptions in persons living with stage D HF who are newly diagnosed with stage D HF (<2 years since initial HF diagnosis) compared to those with chronic stage D HF ( $\geq 2$  years since HF diagnosis that recently progressed to stage D HF). Understanding the differences between these groups will help health-care providers tailor interventions for individuals as they learn to live with stage D HF and progress through the HF trajectory.

# Methods

This study is a secondary analysis of data from a longitudinal study of participants with stage D HF (1RO1NRO13419). The parent study examined critical variations in the palliative care needs of the person living with HF–caregiver dyads in individuals with stage D HF with a less than 2-year predicted survival (10). This study was approved by the university and institutional review boards of participating hospitals, and written informed consent was obtained from all participants upon enrollment. In the parent study, all participants were interviewed monthly, using a semistructured interview format, for up to 2 years. Various aspects of living with HF and changes in their needs and lives as they progressed through the HF trajectory framed the qualitative inquiry. During each interview, participants were asked about changes to their health, activity levels, family dynamics, family role changes, personality and/or mood changes, and spirituality(10). Interviews were audio recorded and professionally transcribed verbatim. Transcripts were de-identified and checked for accuracy by comparing the transcription to the original audio recording prior to analysis by the research team.

The research team for this secondary analysis consisted of the 2 principle investigators (PIs) of the parent study and 2 PhD candidates in nursing. The PIs and PhD candidates each individually analyzed one-half of the interviews. Each interview was analyzed for life descriptions. Data were coded by each research team member independently and then the team met to discuss the codes and form descriptive themes.

Descriptive thematic analysis as described by Miles et al (12) was utilized to better understand the phenomena of life descriptions of persons newly diagnosed and persons with chronic stage D HF as they lived with stage D HF over time. This type of analysis allows data to be categorized in a less interpretive form than other types of qualitative analysis, such as grounded theory and hermeneutic analysis where theories are developed or lively world stories are interpreted, respectively (12). For this analysis, all interviews for the 75 participants were read completely and analyzed to identify life descriptions that were threaded throughout the longitudinal interviews.

During analysis, it became apparent that 12 to 18 months after initial HF diagnosis, perspectives began to slowly change and all participants  $\geq 2$  years from initial HF diagnosis perceived life as a person living with chronic HF, with more negative life descriptions. Therefore, participants were categorized as newly diagnosed (<2 years with stage D HF) or chronic ( $\geq 2$  years with recent progression to stage D HF). Thus, for this study, newly diagnosed participants were those individuals diagnosed with HF for less than 2 years and were found to have stage D HF upon diagnosis or shortly after. The participants with chronic stage D HF were those individuals diagnosed with HF for 2 years or greater who had progressed to stage D HF. This sample is unique in those participants in both the newly diagnosed and the chronic group who have stage D HF.

Descriptions for each group were clustered and compared to determine those that were universal in both the newly diagnosed and chronic participants and those that were unique to the length of diagnosis. Throughout the process of analysis, the descriptions were discussed and presented to the parent study's full research team for validation (13).

# Results

There were 24 newly diagnosed participants and 51 chronic participants (total sample, n = 75; see Table 1 for sample

Participant Groups	Time with HF	Age	SD	Median	Gender, n (%)	Race, n (%)
Newly diagnosed, n = 24 Average Range	7 months 3 weeks-18 months	68 49-89	0.47	0.45 years	F 6 (25); M 18 (75)	Black 3 (12); white 21 (88)
Chronic, n = 51 Average Range	7 years 2-19 years	66 36-88	4.25	6 years	F 15 (29); M 36 (71)	Black 5 (10); white 46 (90)

Table I. Sample Demographics.

Abbreviations: HF, heart failure; SD, standard deviation.



Figure 1. Change in life descriptions of HF over time. HF indicates heart failure.

demographics). Participants in both groups were similar in terms of predicted survival (<2 years) based on the Seattle Heart Failure Model (14). The analysis showed that both groups shared similar life descriptions that changed along a continuum, as shown in Figure 1. These life descriptions (themes) were changing outlook on life, activity adjustments, understanding of HF, and mood. Notable differences between the 2 groups did exist; however, the variations occurred within the same life descriptions (themes). Figure 1 depicts how newly diagnosed participants with HF, even when the initial diagnosis was stage D HF, are naive regarding their expectations of living with HF. As time progressed, the participants slowly came to the realization of the permanency of the functional limitations associated with HF. All participants with a diagnosis of HF  $\geq 2$  years, unless a new intervention was offered (eg, heart transplant or left ventricular assist device [LVAD] implantation), became resigned to the reality of the living with permanent functional limitations (not being able to do daily activities) associated with HF.

# Life Descriptions

Changing outlook on life. Participants' outlook of the future changed as they progressed from naive expectations of returning to pre-illness status, through the realization that these limitations may be permanent, to resignation that they will not get better, but hopeful it does not get any worse. Those newly diagnosed showed hope of getting back to normal or their baseline, as 1 individual in the newly diagnosed group stated, "...going out on the weekends to dance with

my family and friends." Conversely, in the chronic group, persons were hopeful to stay the same and felt uncertainty about their future. This was highlighted by the following participant quote: "You get afraid to live sometimes. You don't make plans, you're afraid to go out on your own sometimes."

Although the outlook was vastly different between the 2 groups, with the newly diagnosed group still hoping for an improved future while most of the participants in the chronic group were living in the present and uncertain about their future, there were some hopeful chronic participants. Sixteen (of the 51) participants in the chronic group were either on the heart transplant list or candidates for an LVAD as destination therapy. Seven of these participants had a more positive outlook about their future. They discussed going back to work, hiking, riding a motorcycle again, and more active living. The possibility that additional interventions could improve outcomes was present for some in the chronic group.

Activity adjustments. As the participants discussed adjustments to their ability to perform activities (eg, cleaning, mowing the lawn, cooking, shopping), the newly diagnosed group described disappointment when unable to do things, whereas the chronic group described disgust that they were no longer able to do activities. The chronic group, typically, did not expect to return to previous activities but lived day-to-day, hoping to maintain the present level of functioning.

To help showcase this theme, 1 participants with newly diagnosed stage D HF said, "I couldn't work. I couldn't do

anything. I couldn't walk 5 steps and I just had to sit in a chair."

The chronic group had a reluctant acceptance of their inability to perform activities and just listed the things that they could not do anymore, for example, "I can't cut the grass. I can't walk. I can't shovel the snow." Another chronic group member stated, "Sometimes you sit and look out of the window and get disgusted-but then realize you should be thankful for whatever the day brings. You accept what you can do and what you can't do."

The above quotes illustrate that participants in the chronic group are resigned to what they can no longer do, whereas the newly diagnosed group still are not realistic about the severity of their illness and show hope of returning to their previous level of functioning.

Understanding of HF. Understanding of HF varied between the 2 groups but not as much as 1 would anticipate. This was surprising because the participants with chronic HF, although having recently progressed to stage D, have had HF for years. When describing HF, both groups talked in fairly simplistic terms, for example, a participant in the newly diagnosed group stated, "My heart is not pumping the fluid around for some reason." By contrast, participants in the chronic group seemed to have somewhat of a better understanding of HF as 1 person stated, "My heart is at 20% ... It means it's not functioning to the best of its ability." The quote by the person in the chronic group reflects a basic understanding of how well their heart is pumping based on physiological tests.

Both groups had an understanding that diet impacted their disease and they had to do things in moderation. The newly diagnosed group also learned that many of their previous habits needed to change (eg, smoking). For example, 1 participant stated, "I'm going to have to change certain things I do. No smoking- that's going to stop... and the eating right, the hardest part is going to be eating right." Many participants in the chronic group also knew that they had to monitor their fluid intake and were able to titrate their diuretics. Example quotes from the chronic group to support these concepts included, "I do my daily weights in the morning and watch my food intake" and "I have Lasix, I have bumex and I have zaroxolyn. I also have spironolactone as the savior. Now if I use the Lasix I don't use the zaroxolyn, those two are interchangeable the other two are not. Sometimes you know you can feel the one stop working you can see you're putting on a little poundage and the ankles are a little bit sore. When that happens, I switch the other pill and I call my doctor so it's documented."

In this sample, over time, the participants understood more about self-care; however, a low salt diet and taking medications were discussed as the main way of controlling exacerbations. Neither group had an in-depth understanding of the disease process.

*Changes in mood.* A change in mood was the fourth life descriptor that emerged from the data. The newly diagnosed

group displayed more shock and disbelief of the diagnosis ("never expected this") and a few showed signs of depression; however, the majority of participants showed no change in mood, as shown through the following participant quote, "My philosophy is it happened and I got to deal with it. I mean sitting here saying 'oh me oh my, why me' don't do a whole lot of good. It happened so you go with the flow." The chronic group was short-tempered and some said they were depressed. Exemplar quotes from the chronic group included, "I just feel down, this could be it, I may never get out of here and never go home" and "Yeah, I guess I'm crabbier." As with the other life descriptions, the above quotes illustrate how the participant's mood changed over the course of living with HF.

# Discussion

This study included a group of participants who were all diagnosed with stage D HF with a life expectancy of <2 years. This study provided a unique opportunity to understand and compare the life descriptions of this population as they traverse the trajectory of stage D HF.

The newly diagnosed group was not only dealing with the "shock" of the initial HF diagnosis but also with the diagnosis of HF at an advanced stage. The chronic group had lived with HF for an average of 7 years and had progressed to stage D. Even with the long history of HF, this group did not verbalize a true understanding of the severity of their HF.

Participants with both the newly diagnosed and chronic stage D HF described the same 4 life descriptions but from different perspectives. The newly diagnosed group was more often hopeful and lacked an understanding of the severity of the disease, whereas the chronic group had become resigned to the permanency of the limitations of living with HF. The newly diagnosed group was often still looking toward the future, whereas the chronic group seemed to live in the present. This is consistent with previous research, which demonstrated that individuals newly diagnosed with HF attempted to continue their day-to-day activities, such as cutting the grass but could not manage (15,16). This occurred along a continuum, with all persons living with chronic stage D HF  $(\geq 2 \text{ years diagnosis})$  having the realization of the permanency of their HF and reluctantly accepting the life that they were facing. This is consistent with other themes found in the literature, including altered self-image and feeling imprisoned by their HF (9).

Although this research study does not provide the answer to why persons' perceptions change over time, one must wonder whether it is because the newly diagnosed group is still in disbelief and has not been exposed to the complications and frequent hospitalizations that occur as one lives with HF. This would be consistent with previous studies that reported experience with a disease impacts self-care expertise and symptom recognition (17,18). Further research is needed to longitudinally follow the changes in life descriptions in the newly diagnosed group. In addition, this information highlights the need for health-care providers to be more diligent in assessing and treating the mental health of those diagnosed with chronic HF. It is not surprising that the chronic group experienced a decline in their mood, as previous research showed that persons living with HF find it to be disruptive, turbulent, and a constant threat to their health (9). In addition, depression has been associated with less effective retention of HF self-care educational materials, (19) and this was consistent with the finding from this study by the participants' lack of knowledge related to HF management and the disease process.

Previous studies have suggested that persons with HF should be stratified into various categories ranging from the first phase of early HF, often highlighted by frequent hospitalizations, to the final phase occurring near the end of life (18). Although this study did not focus on hospitalizations, it does support the idea that persons with HF move through various stages during their illness, highlighting the importance of recognizing the specific needs of persons living with stage D HF when planning care. Similarly, a qualitative analysis reported that persons with HF gradually come to terms with their diagnosis and take on a new life identity; eventually accepting and adjusting to their HF diagnosis (16). Although this study did not identify all stages demonstrated by Stull and colleagues, (16) it did show that persons with HF move through stages ranging from naive expectations to resignation. Finally, our results were consistent with a qualitative inquiry by Thornhill and colleagues that found persons living with HF experience issues with changes in activities and lifestyle and also negative emotions (20).

# Implications for Practice

The results of this study provide new knowledge for healthcare providers. Persons living with stage D HF move along a continuum ranging from naive expectations to resignation in accordance with the length of time since diagnosis. By understanding this movement, health-care providers can appropriately implement strategies consistent with the specific needs of the individual. For example, health-care providers can provide persons with stage D HF with more person-specific education about the illness, since this study identified a learning need in this area. Through this personspecific education, health-care providers can help persons living with stage D HF and their caregivers implement appropriate self-care strategies to improve health outcomes. This may also be an opportune time to discuss diet and symptom monitoring to attempt to prevent exacerbations of the disease. Although palliative care should be offered to the newly diagnosed stage D HF group, they may not be willing to accept these services because they are still in disbelief about the diagnosis. Once persons living with stage D chronic HF have to some extent become resigned to their fate, mental health services may be warranted as this group showed more negative mood changes. Health-care providers must assess persons living with HF in terms of their acceptance of the disease and make the appropriate referrals as indicated by the assessment.

## Strengths and Limitations

A strength of this study is the longitudinal design. The limited evidence that currently exists is cross sectional. This study provides the life descriptions of persons living with stage D HF over time. This is important information that needed to be collected through a qualitative approach so that a deeper richer meaning of the participants' words could be gained and the process of living with stage D HF could be understood from within the context of time from diagnosis. Being the first study to undertake this inquiry, a qualitative study was a good fit.

Limitations to this study include that it is a secondary analysis; however, the authors did have the advantage of access to the participants during follow-up interviews for clarification purposes. In addition, the findings cannot be generalized beyond the scope of persons living with stage D HF. Recommendations for future research include original qualitative inquiry into life descriptions of persons living with stage D HF to better understand this phenomenon.

# Conclusions

Persons living with stage D HF have unique needs that change as the disease progresses. Although both the newly diagnosed and chronic stage D HF groups' life descriptions are the same, they presented unique perspectives of each life description. By understanding the needs of these individuals and how they change over time, health-care providers can anticipate the needs of persons with HF. Future research should investigate interventions based on time from diagnosis to address the changing needs in these 2 populations.

## **Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Research reported in this manuscript was supported by National Institute of Nursing Research of the National Institutes of Health under award number 1RO1NRO13419. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Judith E Hupcey is a professor of nursing, medicine, and bioethics and is the associate dean for graduate education and research at the Pennsylvania State University, College of Nursing. She is also a Fellow in the American Academy of Nursing. She has over 75 publications and book chapters. She received an F32 NRSA postdoctoral fellowship and has been funded by NIH/NINR and The American Heart Association. She also received over \$3.5 million dollars in programmatic funding through HRSA. Her present research focuses on persons with heart failure at end of life and their family caregivers.

Lisa Kitko is an associate professor in the College of Nursing at The Pennsylvania State University. Dr Kitko's main research area is the end-of-life needs of advanced heart failure patients and their family caregivers. Her current clinical research is focused on identifying the palliative care needs of advanced patients with heart failure , the end-of-life trajectory of patients living with mechanical circulatory support, and improving palliative care throughout the end-of-life trajectory through health-care system-based improvements. Dr Kitko has been disseminating her findings as evidenced by manuscripts published in high impact peer-review journals and through presentations at the national and international levels.

**Windy Alonso** is a post-doctoral research associate at the University of Nebraska Medical Center. Dr Alonso's program of research focuses on the needs of individuals with advanced heart failure undergoing left ventricular assist device therapy. She is currently examining outcome disparities experienced by those individuals with LVADs living in rural locations and developing an intervention suited to the needs of this unique population. Dr Alonso is an advocate for rural health and was recently selected as a 2018 National Rural Health Association Rural Health Fellow.