Patient Perceptions of Factors That Influence Self-Management of Heart Failure



Ludmila Santiago-Rotchford, MSN, APRN, ACNS-BC, PCCN

University of Delaware, Newark, De

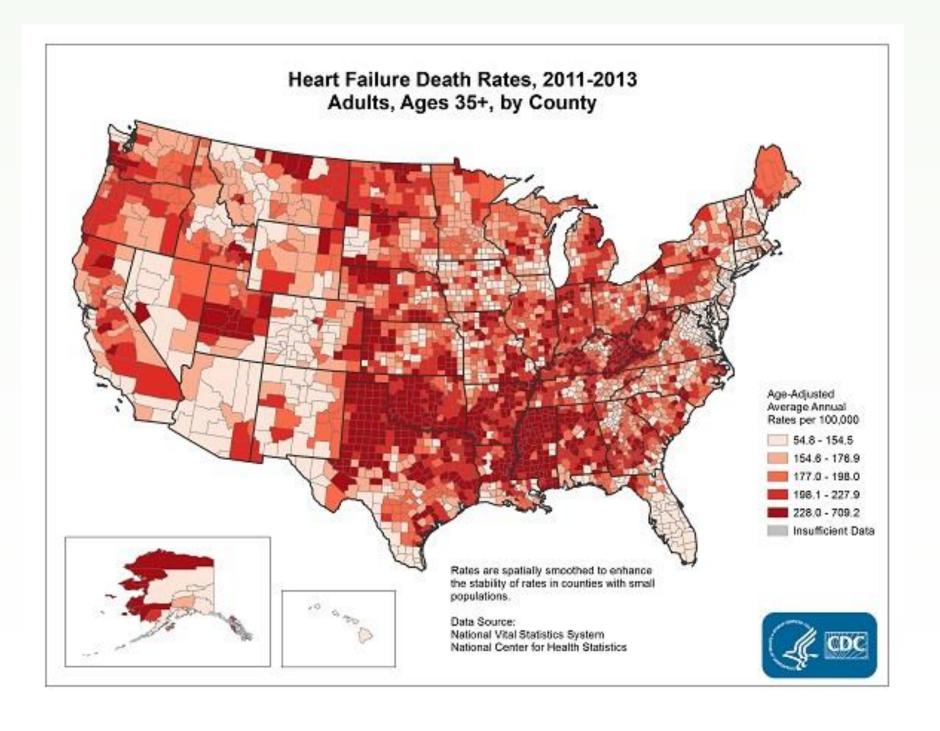
OBJECTIVES

- The learner will be able to discuss patient perceptions of managing symptoms of heart failure.
- The learner will be able to identify behavior modifications by patients with moderate severity of heart failure.

BACKGROUND

Symptoms reported by patients with the chronic condition of heart failure can be ambiguous (Clark, Savard, Spaling, Heath, Duncan, et al., 2012) related to lack of knowledge of what symptoms to report to healthcare providers (Spaling, Currie, Strachan, Harness, & Clark, 2015). A crucial component of managing chronic conditions is self-care management. Tsai, Wang, Lee, Tsai, & Chen (2015) describe three domains of self-care 1) self-care maintenance in which prescribed treatments are followed, 2) self-care management in which decisions of adherence to these treatments is in response to symptoms, and 3) self-care confidence which is a reflection of how confident one feels with the decisions made. Some studies have measured adherence by self-reporting of behaviors (Stut, Deighan, Cleland, & Jaarsma, 2015), using web based applications to monitor daily behaviors (Dorsch, Farris, Bleske, & Koelling, 2015), and specialized questionnaires such as the Symptom Status Questionnaire-Heart Failure (SSQ-HF) (Heo, Moser, Pressler, Dunbar, Martin, & et al., 2015) to quantify patient perceptions of symptom management and severity.

Although there has been an abundance of studies conducted in recent years on heart failure there are limited numbers of studies exploring the factors that influence patients with heart failure to seek medical care or treatment based on self-perceptions of exacerbation of symptoms. Several studies have indicated a need to identify personal perspectives on symptom management in patients with heart failure (Reeder, Ercole, Peek, & Smith, 2015), (Ivynian, DiGiacomo, & Newton, 2015). There are a number of symptoms identified as triggers of exacerbation of heart failure. Some studies identified as many as 29 characteristics of heart failure (Souza, Zeitoun, Lopes, Oliveira, Lopes, & Barros, 2015). This study will focus on symptoms that have an observable consequence by participants such as that of leg edema with weight gain (Kataoka, 2015), performance measures of functional limitations and mobility (Herr, Sayler, Flattery, Goodloe, Lyon, & et al., 2015), and will be limited to patients with NYHA class III and IV heart failure (figure I). Decisions to change behaviors in self-management of heart failure have been measured with respect to adherence to dietary restrictions of daily sodium intake to 2000-3000 mg and fluid intake to 1.5 to 2 liters of fluid daily (Parrinello, Greene, Torres, Alderman, Bonventure, & et al., 2015) which can be controlled by severity of thirst (Allida, Inglis, Davidson, Lal, Hayward, & et al., 2015), or may change after improvement of heart function by mechanical devices such as implantable cardioverter Defibrillators (ICDs) (Balci, Balci, Akboga, Seri, Acar, et al, 2015). According to the CDC, approximately 50% of the people diagnosed with heart failure die within 5 years of diagnosis (CDC, 2016). Rates of death from heart failure 2011-2013 are displayed below.



METHODS

Participants for this qualitative pilot study were three patients with moderate to severe heart failure. Semi-structured interviews were conducted of these patients who were classified under the New York Heart Association class III or IV for heart failure (Figure I). They were interviewed about how they altered their behaviors and medications in response to symptom management. Data was labeled according to symptoms and management of those symptoms and coded. Themes were identified with exemplars from the transcriptions

Figure I. NYHA classes for heart failure

Class Patient Symptoms

- No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea (shortness of breath).
- Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath).
- Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea.
- Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases.

RESULTS

All three participants were married and Non-Hispanic, and included two Caucasian males, and one African American female. Their ages were 69, 51, and 54, respectively, with at least one co-morbidity in addition to heart failure. An ejection fraction of the left ventricle of the heart less than 35% is a standard objective assessment in the diagnosis of significant heart failure (Kusumoto, et al., 2014). All participants reported an ejection fraction ranging between 10% to 25% with an insertion of an automatic implantable cardioverter-defibrillator (AICD) within the last five years. The industry standard is insertion of an AICD due to the high risk of ventricular arrhythmias for patients with reduced ejection fractions (Kusumoto, et al., 2014). Symptoms experienced by the participants were described using either "prior to" or "after" insertion of their AICD as a reference point. Two of the three reported having to wear a temporary external defibrillator prior to insertion of their permanent device. Reported symptoms described were consistent with Class IV of the NYHA classification system (Figure I) (AHA, 2016), with reporting of significant improvement of symptoms after insertion of the AICD. Additional co-morbidities that were reported were rheumatoid arthritis, hypertension and asthma, and orthostatic hypotension by each of the participants respectively.

The questions explored descriptions of symptoms and modifications made by the participants relative to: diet, fluid, activity, and medications, and sources of motivation to initiate a particular behavior in the management of their heart failure. Reduced Sodium intake and fluid restriction is recommended by the AHA for patients with heart failure (Yancy, et al., 2013). All reported limiting added salt to their food but they also reported intake of processed meats and or cheese which are high in sodium content. One of the respondents reported being told he had a high Hemoglobin A1C, which can be an indicator of Diabetes mellitus, but denied ever being advised to reduce carbohydrate intake. All participants reported reducing their daily fluid intake which included consuming water, soda, lemonade, and/or coffee but none set a daily limit on amount consumed. One respondent reported reducing fluid intake further when experiencing shortness of breath. Volumes of fluid intake reported ranged from a minimum of 5 drinks (12 to 16 ounces each) to oneperson reporting drinking a lot of water every day, and the other drinking 6 drinks a day and sipping on water all night to moisten his mouth. Weighing oneself can be utilized to measure fluid retention. One person reported only being weighed at the physician offices twice a month and one person reported weighing himself daily. Several themes were related to limiting activity due to worsening symptoms of heart failure was a consistent behavior amongst participants. All participants reported that activity tolerance improved after insertion of AICD. Finally, there was reporting by the participants of external motivational factors to continue to self-manage their heart failure.

RESULTS

Exemplars from Interviews

Symptoms of worsening heart failure (Figure II)

- 'I was so tired I could only walk from the bed to the recliner and then sleep all day"
 - "Not as active as I used to be"
 - "I was a mechanic and could not work on my car"
- "Could not catch my breath" "Had to stay sitting up"
- "Could not sleep at night" "Unable to take a deep breath"
- "Sweat profusely with little activity" "fatigued"
- "I felt like I ran a marathon"
- "sleep in a chair" "insomnia"
- 'right foot would swell up"

Modifying Behaviors (Figure III)

- "I eat three meals a day-I used to only eat supper" 'Used to drink 5 sodas and 2 pitchers of iced tea a day" "used to eat 3-4 sandwiches a day "
- "Buy frozen vegetables"
- "Used to add a lot of salt"
- "I don't go too far from the bathroom after I take my medicine" "Now I have to slow down"
- "I had to retire"
- I am drinking more water"
- "Changed to 2% milk"
- "I do not take my Lasix before appointments"
- "I stay away from salt"
- "I used to walk a lot"
- "I Have not been back to work"
- "Take an extra Lasix once in a while"
- "Skip a dose of Lasix if I am not going to be near a bathroom"
- "Sometimes sleep in a chair"
- "Not able to work"
- "I changed how much I eat not what I eat"
- "Only add salt to spinach and corn"
- "Use a salt substitute"

Motivational factors (Figure IV)

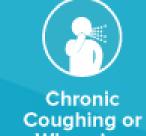
- "It is hard for a grandfather not to be able to play with his grandson"
- "My wife would have to drive"
- "My wife has seizures-I did not want her to get sick"
- "I take my life more seriously"
- "I have grandkids and I have to be better for them"
- "I listen to my body"
- "I have talked to other people with heart failure and everybody is different"

CONCLUSIONS

All participants reported modifying diet, fluid intake, activity, and medication times in response to severity of symptoms. Not all of the participants reported expected symptoms of peripheral edema or shortness of breath, rather the most common symptoms perceived as worsening of heart failure were fatigue and activity intolerance. The chart below is an example of patient education for management of symptoms of heart failure (AHA, 2016). All participants reported improvement of severity of symptoms after insertion of an automated implantable cardioverter-defibrillator. Further research is needed to explore the patient experience with regard to management of symptoms of heart failure.



Do you know the symptoms of HF?













People who experience more than one should be evaluated.

REFERENCES

- Allida, Sabine M, Inglis, Sally C, Davidson, Patricia M, Lal, Sara, Hayward, Christopher S, Newton, Phillip J,. (2015). Thirst in chronic heart failure: A review. JOCN Journal of Clinical Nursing, 24(7-8), 916-926.
- Balci, Kevser Gulcihan, Balci, Mustafa Mucahit, Akboga, Mehmet Kadri, Sen, Fatih, Acar, Burak, Yılmaz, Samet, Ediboglu, Emek, Maden, Orhan, Selcuk, Hatice, Selcuk, Mehmet Timur, Temizhan, Ahmet, Aydogdu, Sinan, (2015). Perceived benefits of implantable cardioverter defibrillator implantation among heart failure patients and its relation to quality of life: A cross-sectional study. Cardiol Ther Cardiology and Therapy, 4(2), 155-165.
- Clark, A., Savard, L., Spaling, M., Heath, S., Duncan, A. & Spiers, J.(2012). Understanding help-seeking decisions in people with heart failure: A qualitative systematic review. International Journal of Nursing Studies, 49, 1582-1597,
- http://dx.doi.org/10.1016/j.ijnurstu.2012.05.010. Dorsch MP, Farris KB, Bleske BE, Koelling TM,. (2015). A web application for self-monitoring improves symptoms in chronic systolic heart failure. Telemedicine Journal and e-Health: The Official Journal of the American Telemedicine Association, 21(4),
- , Salyer, Jeanne, Flattery, Maureen, Goodloe, Lauren, Lyon, Debra E., Kabban, Christine Schubert, Clement, Dolores G.,. (2015). Heart failure symptom clusters and functional status - a cross-sectional study. JAN Journal of
- Heo S, Moser DK, Pressler SJ, Dunbar SB, Mudd-Martin G, Lennie TA, (2015). Psychometric properties of the symptom status questionnaire-heart failure. The Journal of Cardiovascular Nursing, 30(2) Ivynian, S. E., DiGiacomo, M., Newton, P.J.,. (2015). Care-seeking decisions for worsening symptoms in heart failure: A
- qualitative metasynthesis. Heart Fail Rev Heart Failure Reviews, 20(6), 655-671. Kataoka, H.,. (2015). Clinical significance of bilateral leg edema and added value of monitoring weight gain during follow-up of patients with established heart failure. EHF2 ESC Heart Failure, 2(4), 106-115.
- Kusumoto, F., Calkins, H., Boehmer, J., Buxton, A., Chung, M., ... Welikovitch, L. (2014). HRS/ACC/AHA Expert consensus statement on the use of implantable cardioverter-defibrillator therapy in patients who are not included or not well represented in clinical trials. Circulation, 130: 94-125.
- National heart failure rates retrieved August 17,2016 from http://www.cdc.gov/dhdsp/data statistics/fact sheets/fs heart failure.htm
- NYHA classes of heart failure based on patient symptoms. Retrieved April 3, 2016 from
- http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure UCM 306328 Article.jsp#.VwJQwvkrLIU
- Parrinello G, Greene SJ, Torres D, Alderman M, Bonventre JV, Di Pasquale P, Gargani L, Nohria A, Fonarow GC, Vaduganathan M, Butler J, Paterna S, Stevenson LW, Gheorghiade M,. (2015). Water and sodium in heart failure: A spotlight on
- congestion. Heart Failure Reviews, 20(1), 13-24. Reeder KM, Ercole PM, Peek GM, Smith CE, (2015). Symptom perceptions and self-care behaviors in patients who self-manage heart failure. The Journal of Cardiovascular Nursing, 30(1)
- Souza, Vanessa, Salloum Zeitoun, Sandra, Takao Lopes, Camila, Dias de Oliveira, Ana Paula, Lima Lopes, Juliana, Bottura Leite de Barros, Alba Lucia,. (2015). Clinical usefulness of the definitions for defining characteristics of activity intolerance, excess fluid volume and decreased cardiac output in decompensated heart failure: A descriptive exploratory study. JOCN Journal of Clinical Nursing, 24(17-18), 2478-2487.
- Spaling MA, Currie K, Strachan PH, Harkness K, Clark AM,. (2015). Improving support for heart failure patients: A systematic review to understand patients' perspectives on self-care. *Journal of Advanced Nursing*, 71(11), 2478-89.
- Stut W, Deighan C, Cleland JG, Jaarsma T,. (2015). Adherence to self-care in patients with heart failure in the HeartCycle study. Patient Preference and Adherence, 9, 1195-206.
- Symptoms of Heart Failure retrieved August 17,2016 from
- http://www.heart.org/HEARTORG/Conditions/HeartFailure/WarningSignsforHeartFailure/Warning-Signs-of-Heart-
- Tsai, Pi-Kuang, Wang, Ruey-Hsia, Lee, Chee-Siong, Tsai, Liang-Miin, Chen, Hsing-Mei,. (2015). Determinants of self-care decision-making in hospitalised patients with heart failure. JOCN Journal of Clinical Nursing, 24(7-8), 1101-1111
- Yancy, C., Jessup, M., Bozkut, B., Butler, J., Casey, D., ... Wilkoff, B. (2013). 2013 ACCF/AHA Guideline for The management of heart failure: Executive summary. A report of the American College of Cardiology Foundation/American Heart Association task force on practice guidelines. Circulation, 128: 1810-1852.

CONTACT INFORMATION

Ludmila Santiago-Rotchford twinbl@udel.edu