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## Heart failure self-management and normalizing symptoms: an exploration of decision making in the community

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## ABSTRACT

*Objective:* To explore the decision making processes undertaken by community-dwelling individuals with heart failure as they experience symptom changes.

*Background:* Heart failure patients are responsible for daily self-management that includes responding to symptom fluctuations between exacerbations. Despite education, some patients fail to seek timely medical intervention when symptoms change.

*Methods:* Semi-structured interviews were conducted with homecare patients after receiving self-management education. Grounded theory methods and qualitative software were used to collect and analyze the data.

*Results:* Five themes were identified: perceiving symptoms, alleviating actions and control, normalizing symptoms, absence of help seeking behaviors, and decreased functional capacity. Normalizing symptoms included actions taken by participants to mitigate symptom fluctuations. Daily fluctuations were assimilated into normal life resulting in desensitization of symptom recognition and decreased functional capacity.

*Conclusions:* Findings support the need to educate on early symptom recognition, the benefits of safe physical activity, and building a system to support self-management patient-physician collaboration.

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### Introduction

Heart failure (HF) is a leading cause of hospitalization in patients 65 years of age and older, with 90-day readmission rates of 23–50% for Canadian patients aged 75 years and older.<sup>1</sup> HF carries a morbidity rate of 50% at 5 years<sup>2</sup> and is associated with increased frequency and severity of exacerbations at end stage.<sup>3</sup> An estimated 600,000 Canadians<sup>4</sup> and 5.8 million Americans<sup>5</sup> are living with HF, these numbers are projected to increase with the aging population.<sup>1</sup> Access to specialized HF clinics is constrained by geography and volume capacity,<sup>1</sup> leaving the majority of HF self-management education and supports being conducted by primary care within the community.<sup>6</sup>

Self-management is a complex process that includes maintenance, monitoring, and management tasks whereby the patient is required to identify and act on symptom changes.<sup>7,8</sup> Active engage-

ment in daily care includes collaboration with health care professionals.<sup>9</sup> Clinical guidelines emphasize this expectation of patient participation in monitoring and managing symptoms between acute exacerbations.<sup>7,10</sup> Strategies to promote self-management have focused on patient education and knowledge acquisition; including taking medications as prescribed, monitoring weights, oral fluid and sodium intake restrictions. However, education strategies implemented in hospital settings, clinics, and group settings have not translated into successful self-management behaviors in the community.<sup>11–13</sup> Despite efforts to improve self-management, some patients fail to seek early medical attention when their symptoms change,<sup>8</sup> resulting in treatment delays between 3 and 7 days.<sup>14,15</sup> Knowledge does not translate into behaviors,<sup>11–13,16</sup> even when patients are able to recall information and describe actions, implementation of actions remains problematic.<sup>11,17–19</sup> Studies on the determinants of self-management behaviors have been mixed, with quality of life, experience with monitoring, severity of disease, symptom presentation, and nature of competing goals being found to either enhance or inhibit self-management execution.<sup>20–25</sup> Little is known on what the patient is doing in their home environment when their symptoms change. The purpose of this study was to explore the daily experience with self-management, coping mechanisms, symptom recognition, and

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decision-making processes involved in determining the point that help seeking was needed. This study focuses on HF patients residing in the community and how self-management is practiced in daily life, and will inform future strategies to improve self-management interventions.

## Methods

### Study design

This is a grounded theory study using an initial criterion case followed by a theoretical sampling strategy conducted from February–May 2017.

### Ethical considerations

The Institutional Review Board for Ethical Standards in Research from Walden University approved the study (02-13-17-0386). Participants provided written informed consent for the interviews, an alias was assigned to each participant in the reporting of results to ensure confidentiality. This investigation conforms to the principles outlined in the Declaration of Helsinki.

### Participants

Participants were recruited from the community Rapid Response Nurse Program in Southern Ontario using a site-based method of recruitment, with six nurses as the gatekeepers.<sup>26</sup> The healthcare agency is comprised of five community sites covering a population of 1.4 million over a geographical area of approximately 7,000 km<sup>2</sup>. Nurses and site selection was based on availability of full time staff, thereby maximizing flyer distribution. Four sites were targeted for recruitment efforts, ensuring representation from rural and urban areas. The Rapid Response Nurse cares for patients residing in the community with a pre-existing diagnosis of HF. Rapid Response nurses provide self-management education, medication reconciliation, physical assessment, and transitional communication with the patient's primary care physician following a hospitalization. Patients are visited in their home on average three times over a period of one month, visits last approximately an hour in duration. The standard self-management education provided by rapid response nurses is taken from *Managing Heart Failure*,<sup>27</sup> and includes instructions to monitor weights and a HF Zones decision aid. The goals of this provincial program are to facilitate self-management skills, promote optimal states of health, and improve communication during transitions in care.

Study eligibility included: 1) able to understand and speak English sufficient for informed consent and participation in an interview, 2) had experienced a heart failure exacerbation requiring hospitalization in the previous 3 months, 3) had received self-management education, and 4) over the age of 18 years. Patients who had been deemed palliative or had a documented cognitive impairment were excluded. Six rapid response nurses were selected and provided an information session detailing the participant criteria and the purpose of the study. Recruitment flyers were distributed to potential participants. The patients were then free to call the phone number on the flyer if they had an interest in participating in the study, no incentive was offered. Potential participants were reviewed during this initial call to determine if they met inclusion criteria and were able to complete the in-depth interview. Once eligibility was met, interview times were arranged. Written consent was completed on the day of the interview.

The projected sample size was estimated to be between 15 and 22 individuals. Although there is no consensus on the ideal sample size for grounded theory approaches, recommendations range from

**Table 1**

Interview questions

Interview Protocol
Describe what self-management of heart failure means to you.
Describe a typical day of managing heart failure, tell me about your day and how you care for yourself.
How does this change when you notice a change in symptoms or new symptoms?
Describe the symptoms that you are aware of on a daily basis.
Describe the symptoms that you were experiencing at the time of your most recent hospitalization.
Describe what meaning you assigned to how you were feeling just prior to hospitalization.
What symptoms do you find the most concerning or difficult to manage? (Easiest to manage?)
What actions can/do you take when you become concerned about your symptoms?
Describe your feelings over the course of this experience.
Describe what resources/options are available to help you manage heart failure? If you could think of one thing that would help you manage your symptoms what would that be?
What are your goals for managing your heart failure?
Is there anything else you would like to share?

10 to 30 cases to achieve saturation.<sup>28,29</sup> Quality of data was the criterion for saturation in this study. Saturation was demonstrated during data analysis, whereby themes rich in contextual properties and relational statements resulted in thick descriptions and a graphic representation.<sup>30</sup>

### Data collection

One face-to-face interview was completed with each of the 18 participants. An interview protocol with semi-structured questions was used to collect the data. The interview protocol (Table 1) contained 14 questions based on a review of the literature; as the study progressed, additional probes were added focusing on the emerging themes. Open-ended questions were used to allow the participant to share their personal experience of living with and managing heart failure symptoms. Participants were given the option of completing the interview at a location of his or her choice, all participants selected their home. During the interview observations and contextual data were hand written as field notes, while researcher reflections were immediately documented after leaving the participants home.

Basic demographic and health information was collected from the participants by self-report. Half of the participants did not know their left ventricular ejection fraction. New York Heart Association Functional Classification was determined from the interview questions that prompted answers on activity levels and daily symptoms. Medications were reviewed at the time of the interview. All interviews were conducted by one investigator (N1) who is a registered nurse with cardiology experience trained in qualitative interviewing.

The interview process began with allowing the participant to describe what self-management means to them, their experience in self-managing, and the symptom experience. Participants were encouraged to elaborate on what they thought about when their symptoms changed, the perceived options or resources, and what they were feeling in that moment. Responses were clarified and probed for deeper meaning as themes emerged during the interview, a post interview debrief ensured respondent validation and strengthened credibility.

### Data analysis

In keeping with grounded theory methodology, data analysis was conducted along with data collection. Interviews were digitally

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