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## Personal growth, symptoms, and uncertainty in community-residing adults with heart failure

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### ABSTRACT

**Background:** Personal growth has not been studied extensively in heart failure (HF).

**Objectives:** To characterize personal growth in HF and its relationships with symptom burden, uncertainty, and demographic and clinical factors.

**Methods:** Associations among personal growth, uncertainty, symptom burden, and clinical and demographic variables were examined in adult outpatients with HF using bivariate correlations and multiple regressions.

**Results:** Participants ( $N = 103$ ; 76% male, mean age = 74 years, 97% New York Heart Association classes II and III) reported moderate levels of personal growth, uncertainty, and symptom burden. Personal growth was weakly correlated with age and symptom burden but not with other study variables. In a regression model, age, sex, ethnicity, disease severity, time since diagnosis, symptom burden, and uncertainty were not significant independent correlates of personal growth.

**Conclusions:** Community-residing patients with HF report moderate personal growth that is not explained by uncertainty, symptom burden, or demographic and clinical variables.

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### Introduction

Heart failure (HF) is a chronic, progressive disease that is associated with significant symptom burden, diminished quality of life, and high mortality.<sup>1</sup> More than 5 million adults in the United States are living with HF, a population that is expected to increase to more than 8 million in the next 15 years.<sup>2,3</sup> By age 40, men and women have a 20% lifetime risk of developing HF.<sup>3</sup> Despite improvements in HF management and survival in the United States, many progress to advanced stages, and approximately 50% of individuals with HF still die within 5 years of diagnosis.<sup>3</sup> Accordingly, a diagnosis of HF can be a life-altering event characterized by significant adversity.

HF is characterized by an array of symptoms that may occur in isolation or together, with varying degrees of frequency, severity, distress, and patterns of onset or relief.<sup>4–7</sup> Ambiguity in symptom patterns and the ability to recognize certain symptoms as relevant to HF add to the challenges of living with HF.<sup>7–9</sup> People living with HF commonly report uncertainty related to symptoms, changes in health status, day-to-day planning, and anticipation of death.<sup>10–19</sup>

Despite many challenges, people coping with serious chronic conditions (e.g., cancer, human immunodeficiency virus [HIV] or acquired immune deficiency syndrome, coronary artery disease [CAD], multiple sclerosis) may nonetheless report personal growth.<sup>20–24</sup> Personal growth has been conceptualized as an individual's ability to perceive new opportunities or positive changes in personal values, priorities, abilities, or relationships in response to adversity. In research with individuals living with life-altering illnesses, personal growth is commonly referred to as post-traumatic growth. However, it has also been characterized as adversarial<sup>25</sup> or stress-related growth,<sup>26,27</sup> thriving or benefit-finding,<sup>28–30</sup> and psychological or disease adjustment.<sup>20</sup> In general, personal growth is an outcome that is congruent with the goals of supportive models of care, such as palliative care, that aim to supplement traditional disease management in HF by enhancing psychosocial and spiritual well-being.<sup>1,31–36</sup> To the extent one's condition or health status is characterized by ongoing uncertainty, reduction or reappraisal of uncertainty (e.g., as an opportunity) may facilitate personal growth.<sup>37–39</sup>

The relatively few studies that have examined personal growth in cardiac populations have been conducted primarily among patients with CAD who survived and recovered from myocardial infarction (MI) or cardiac arrest. In these populations, personal growth has been shown to be related to a decreased incidence of MI

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re-occurrence over 8 years after an initial MI.<sup>40</sup> In patients with cardiac conditions, personal growth has also been associated with lower levels of psychological distress<sup>21</sup> and depression,<sup>23,41</sup> social support<sup>23</sup> and strengthened family relationships,<sup>40</sup> positive coping,<sup>41,42</sup> and better overall mental health and general well-being.<sup>21,41</sup> Personal growth has also been associated with personality traits such as higher levels of extraversion and conscientiousness and lower levels of neuroticism.<sup>41</sup>

Two longitudinal studies conducted in Canada examined post-traumatic growth in patients with cardiac conditions, including HF.<sup>22,23</sup> Higher levels of growth were found among participants who were female,<sup>22</sup> non-White,<sup>22</sup> and younger,<sup>22,23</sup> and who perceived their disease as both serious and responsive to treatment.<sup>23</sup> Higher levels of growth were associated with greater use of non-urgent health services (outpatient physician visits and cardiac rehabilitation), but not with readmissions or emergency department visits.<sup>22</sup> However, less than 15% of participants assessed for personal growth in either study had HF.<sup>22,23</sup> Thus, the extent to which personal growth might be characteristic of patients with HF is unclear.

Among patients living with other serious illnesses, higher levels of personal growth or benefit-finding have been associated with positive outcomes, including increased survival after chemotherapy for hepatocellular carcinoma,<sup>43</sup> decreased mood disturbance<sup>44</sup> and better adherence with antiretroviral medication in HIV disease,<sup>45</sup> adaptive coping in multiple sclerosis,<sup>46</sup> decreased mood disturbance in patients with cancer and lupus,<sup>47</sup> and better physical functioning<sup>48</sup> and less pain-related activity limitation in patients with rheumatoid arthritis.<sup>49</sup> Research on the association between demographic and clinical factors (e.g., disease severity, time since diagnosis) and personal growth in a variety of disease populations has generated mixed results.<sup>20</sup> A better understanding of personal growth in HF and factors that contribute to it may help to inform the development of holistic, patient-centered models of care. Therefore, we conducted a study to determine the association of personal growth with demographic and clinical factors, uncertainty, and symptom burden in patients with HF.

## Theoretical frameworks

The study was guided by 2 theoretical perspectives: Mishel's reconceptualized uncertainty in illness theory (RUIT)<sup>38,39</sup> and the post-traumatic growth model of Tedeschi and Calhoun.<sup>50</sup> The RUIT describes how individuals living with chronic illness may be able to positively reappraise ongoing uncertainty, move beyond basic adaptation, and achieve growth through the discovery of new life meaning and acceptance of change. In addition, the RUIT considers the influence of time, disease severity, and symptoms on uncertainty.<sup>38,39</sup> Post-traumatic growth is characterized by some degree of personal transformation that evolves from grappling with a life-threatening event or from coming to terms with a chronic situation or medical diagnosis that disrupts an individual's life. Post-traumatic growth often involves changes in an individual's fundamental beliefs about the world and his or her role in it.<sup>50</sup>

## Aims

The objectives of this study were to describe the levels of personal growth in adults with HF and to examine the associations between symptom burden, uncertainty, disease severity, time since diagnosis, age, sex, and ethnicity and personal growth.

## Methods

### Design, sample, and setting

A descriptive, exploratory design with cross-sectional data collection was used to study a convenience sample of HF patients ( $N = 103$ ) from an outpatient cardiology clinic in Texas. Data collection occurred between January and August 2014. Patients were included if they were 18 years of age or older, met criteria for New York Heart Association (NYHA) class II to IV HF, lived in the community, were able to speak and understand English, and were capable of providing informed consent.

A priori power analysis indicated that a sample size of 102 would be sufficient to achieve 80% power to detect a medium effect size ( $f^2 = .15 \approx R^2 = .13$ ) for a regression model with up to 7 independent variables at an alpha level of .05.

### Procedure

The study was approved by the Human Research Review Committee (HRRC #13–581) of a southwestern US academic health sciences center. Signed informed consent was obtained from all participants.

Recruitment letters from clinic letterhead were sent to 180 potentially eligible patients who were identified using HF diagnostic criteria alerting them to the study and to its endorsement by the clinic. Recruitment flyers were available in the cardiology clinic and given to HF patients by providers during scheduled visits.

Patients who expressed interest met with the principal investigator either at the time of their appointment or at another mutually convenient time. A total of 107 patients participated (94 recruited in person and 13 by letter). Two participants withdrew from the study and 2 did not return surveys, resulting in a final sample of 103.

Participants were given the option of completing a survey that combined multiple questionnaires to assess personal growth, symptom status, uncertainty, and clinical and demographic characteristics either electronically via a secure web portal (Research Electronic Data Capture [REDCap™])<sup>51</sup> or on paper, either independently or via an interview. The majority (58%) completed the survey via an in-person interview, 40% completed it independently on paper, and 2% completed it electronically. Interviews were conducted by the principal investigator in a private office and typically lasted 20 min. Supplementary clinical data were primarily collected from the medical record or, in a few select cases, via provider report. All data that were documented on paper were entered into REDCap™ by the principal investigator.

### Variables and measures

#### Personal growth

Personal growth was measured using the total score from the Posttraumatic Growth Inventory (PTGI), a 21-item instrument that measures an individual's perceptions of favorable changes that occur as a result of dealing with a traumatic life event.<sup>52</sup> Participants are asked to rate the degree of change that occurred as a result of an adverse life event, in this study their HF diagnosis, on a 6-point Likert scale, with 0 indicating no change and 5 indicating the greatest degree of positive change. A total growth score is calculated by adding the individual item scores. The maximum total growth score that can be obtained is 105. The 21 items comprise 5 subscales: New Possibilities, Relating to Others, Personal Strength, Appreciation of Life, and Spiritual Change. The PTGI has been used to evaluate positive outcomes perceived by patients living with cancer; heart disease; HIV; and neurologic, orthopedic, and burn

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