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Behaviors, treatments, and self-management strategies used by patients and caregivers at home

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Heart failure (HF) is a significant and progressive syndrome affecting approximately 6 million Americans 20 years of age or older, and is expected to impact more than 8 million Americans 18 years or older by 2030.1 National data demonstrate HF is among the top four principal diagnoses leading to 30-day all-cause hospital readmissions, with a 30-day readmission rate ranging from 22.9% to 56%.1,2

During the COVID-19 pandemic, however, reduced admissions for HF were seen worldwide.3-4 Hospitals reported a drop in HF volume corresponding with the initial wave of the COVID-19 pandemic in March to May 2020 of 30% to 90%, with the highest reduction observed in Japan.3-4 Of course, during the COVID-19 pandemic, everyone—particularly those with serious chronic diseases such as HF—was encouraged to socially distance themselves from others to limit the risk of contracting SARS-CoV-2. Emerging research indicates that social distancing and limited exposure to others (or quarantine) has impacted how patients managed their HF symptoms at home as they attempted to avoid hospitalizations.3,5-7 Strategies used to reduce ED visits and subsequent hospitalization were the use of alternative communication and monitoring telephonically.3,5-7

HF is a multifaceted chronic disease, and daily management of symptoms is extremely complex. People with HF are expected to be knowledgeable and confident in their ability to maintain and self-manage their symptoms and to identify when these symptoms progress.8 The American Heart Association (AHA) has published evidence-based practice recommendations for the care of patients with HF, which support reductions in 30-day readmission rates.9 Recommendations focus on education in the acute care setting regarding appropriate self-care practices and medication regimens that patients should follow at home.9 Studies have demonstrated that successful self-care among patients with HF depends on patient education with a focus on self-care, medication management, diet, and routine medical outpatient follow-up and support.8,10,11 Evidence also suggests that in the absence of high-quality patient education, appropriate self-care, and routine follow-up with their provider, patients with HF are frequently readmitted to the hospital because they can’t manage their symptoms effectively at home.12,13

Traditional transitional strategies aimed at reducing HF readmissions are focused on postdischarge follow-up phone calls, education interventions, clinical interventions, homecare (including in-home diuretic infusion), remote monitoring of weight gain, and medication adherence.14 These strategies take a predominantly reactive approach to disease management, and don’t directly address patients’ psychosocial needs or specific
goals for patient education.\textsuperscript{15} In addition, despite the benefits of medical follow-up, at least 8% of follow-up appointments aren’t kept, leading to increased needs for support and education.\textsuperscript{16}

Patients face a significant challenge upon discharge to home due to the variety of skills required for self-care, compounded by the overall impact the disease has on their lives.\textsuperscript{15} This challenge leaves patients feeling unprepared and overwhelmed.\textsuperscript{15} However, caregivers play a pivotal role in ongoing HF care and can positively impact patient outcomes. Despite the important role caregivers provide, they report a lack of confidence in decision-making and knowledge of self-care practices. In fact, many caregivers are concerned that they may be providing incorrect information to the patients they support.\textsuperscript{17} It’s important to establish proactive support programs in the community for both patients and caregivers aimed at providing opportunities for social support and education to support self-efficacy, build self-care behaviors, and improve decision-making.\textsuperscript{15}

The aims of this study were to identify the factors contributing to a reduction in readmissions for patients with HF during the initial phase of the COVID-19 pandemic; to determine how confident patients were in managing their HF at home; and to describe the behaviors, treatments, and self-care strategies used by patients or caregivers to manage HF symptoms at home. Identifying factors, behaviors, and strategies may be useful to help ensure the health of the HF population at home and continue to support reduced inpatient admission.

**Research questions**

1. Was there a reduction in HF readmission in patients with an existing diagnosis of HF during the initial phase of the COVID-19 pandemic at this institution?
2. Are patients with HF and caregivers confident in managing HF at home?
3. What were the behaviors, treatments, and self-management strategies used at home by the patient or caregiver to manage HF symptoms during the initial phase of the COVID-19 pandemic?

**Methods**

**Study design**

This study was guided by a patient- and family-centered care model and used a quantitative descriptive design with both a retrospective review of existing data from the electronic health record (EHR) and telephone surveys of patients or their caregiver.\textsuperscript{18} Demographic variables, including marital status, caregiver support, age, and gender, were collected through the EHR. Researchers developed and asked additional questions regarding patients’ interactions with clinicians during the COVID-19 pandemic, use of telehealth, and perceptions of seeking or avoiding seeking care. Questions associated with the Self-Care of Heart Failure Index (SCHFI) for patients or the Caregiver Contribution to Self-Care Heart Failure Index (CCSCHFI) for caregivers were also included. Institutional Review Board approval was obtained prior to study initiation and participant verbal consent was obtained at the start of the phone call followed by a mailed hardcopy for their records.

**Inclusion criteria**

The study included all patients 21 years and older who were admitted to the hospital December 1, 2019, to February 29, 2020, with a diagnosis of HF (pre-pandemic period). Additionally, it included all patients 21 years and older who were admitted to the hospital March 1, 2020, to May 31, 2020 (pandemic period), with any of the following conditions: (1) HF; (2) SARS-CoV-2 with a comorbid diagnosis of HF; or (3) SARS-CoV-2 and received HF-related care and at least two HF-related care treatments or interventions (diuretics, HF-related lab testing, HF-related imaging with confirmed fluid overload, or reduced ejection fraction).

**Exclusion criteria**

All patients who died or were discharged to hospice were excluded. Individuals who didn’t speak English were excluded from the telephone survey.

**Sample size**

This study had two phases. The first phase used a cohort sample size of 238 patients diagnosed with HF in the prepandemic study period. Of those patients, 205 met the inclusion criteria to answer research question number one. To answer research question number two, the second phase of the study used the aforementioned cohort sample of 205 minus 18 patients who were readmitted, leaving 187 patients who had an HF diagnostic code (International Classification of Diseases, 10th revision) and no readmissions between March 1, 2020, and May 31, 2020. Of the 187 patients, only 117 spoke English and had a valid telephone number; of
these, 44 patients or caregivers answered their phone and 15 declined to participate. The final sample included 29 patients who agreed to participate and completed the telephone survey. A sample size as small as 22 provides sufficient power to detect a large effect size (such as, Cohen d > 0.62) using a one-sample t-test at alpha = .05 when comparing the average SCHFI score in this sample with the historical population cut-off score of 70 (R Studio, 2021, Vienna, Austria).

Instruments
The second phase of the study used the SCHFI or the CCSCHFI, depending on whether the patient or caregiver agreed to participate in the study. Scores range from 0 to 100; higher scores indicate better self-care. The SCHFI and the CCSCHFI are both valid and reliable instruments (Cronbach alpha, 0.70–0.82 and 0.80, respectively).

The level at which HF self-care is deemed adequate and effective in improving health outcomes is 70 or greater as measured by the SCHFI. The surveys also included a brief demographic section and an option for open-text responses about the study participants’ experiences at home regarding self-care and symptom management.

SCHFI. The SCHFI is a widely used self-assessment instrument with 39 questions spanning four sections that measure the maintenance, symptom perception, management, and confidence of patients’ self-care of their HF.

• Section A consists of 10 items; each item is rated on a 1 to 5 scale: (1) Never, (3) Sometimes, (5) Always.
• Section B consists of 10 items; each is rated on a 1-5 scale: (1) Never, (3) Sometimes, (5) Always. This section also has two additional items that are rated on a 0-5 scale and include a not applicable (NA) option: (NA) have not had symptoms, (0) I did not recognize the symptom, (1) not quickly, (3) somewhat quickly, (5) very quickly.
• Section C consists of seven items rated on a 1-5 scale: (1) not likely, (3) somewhat likely, (5) very likely. There’s one additional item that’s rated on a 0-5 scale: (0) I did not do anything, (1) not sure, (3) somewhat sure, (5) very sure.
• Section D consists of 10 items rated on a 1-5 scale: (1) not confident, (3) somewhat confident, (5) extremely confident.

CCSCHFI. The caregiver index has three sections measuring maintenance, management, and confidence; it’s focused on what the caregiver does for the person with HF.

• Section A consists of 10 items; each item is rated on a 1-5 scale: (1) never, (3) sometimes, (5) always.
• Section B consists of 9 items; each is rated on a 1-5 scale: (1) never, (3) sometimes, (5) always. This section also has two additional items that are rated on a 0-5 scale and include an NA option: (NA) has not had symptoms, (0) I did not recognize the symptom, (1) not quickly, (3) somewhat quickly, (5) very quickly.
• Section C consists of seven items rated on a 1-5 scale: (1) not likely, (3) somewhat likely, (5) very likely. There is one additional item that is rated on a 0-5 scale: (0) I did not do anything, (1) not sure, (3) somewhat sure, (5) very sure.

Data analysis
Data were extracted from the EHR for all patients admitted between December 1, 2019, and May 31, 2020, with any of the aforementioned inclusion criteria and categorized into the prepandemic or pandemic groups. Data were analyzed to determine how many patients in the prepandemic period were also hospitalized in the pandemic period. Sample characteristics of participants in the prepandemic group were examined relative to participants seen during the pandemic using comparative statistics (t tests, χ²). Last, prepandemic participants admitted for

Despite the pandemic disrupting in-person care, many participants reported they’d sustained follow-up with their providers either through telemedicine or phone calls.
HF-related care who didn’t have a subsequent admission during the pandemic period were contacted and asked to participate in a brief telephone survey.

Descriptive statistics were used to examine the sample’s responses, and one-sample $t$ tests as well as nonparametric equivalent statistical approaches (Wilcoxon test) were used to compare the sample’s SCHFI scores to that of general populations. Effect sizes were computed for each statistically significant finding using Cohen $d$ for the $t$ test and $r$ for nonparametric tests. For any significant finding, at $P < .05$, 95% confidence intervals (CIs) were computed.

**Results**

**Overall sample characteristics.** Overall, 29 of a possible 117 patients/caregivers completed this study, representing 24.8% of eligible participants. The sample was primarily men (62%) who lived at home (100%) with a spouse, partner, or child (62%). Twenty-seven percent of the patients had a visiting nurse who would come to the house and see the patient regularly, whereas the remaining 11% of the patients lived alone without additional in-home support. The mean age of the sample was 75.7 (SD, 11.94) years. There were seven surveys in which the caregiver provided information (24.1%).

**Research question #1: Readmission data during the height of the COVID-19 pandemic.** Again, a total of 866 patients in the full dataset had been diagnosed with HF during the entire study period. Of these, a total of 256 patients with HF were seen in the prepandemic period and 205 patients met inclusion criteria. Of these, only 18 (8.8%) were readmitted for HF-related care after February 29, 2020, and 187 (91.2%) were not readmitted after February 29, 2020. No statistically significant differences were observed in patient characteristics between those readmitted ($n = 18$) and those who weren’t ($n = 205$). (See Table 1.)

**Research question #2: Level of confidence in self-management of HF.** The $t$ tests indicated that the sample’s SCHFI scores were statistically significantly below expected SCHFI score levels of HF self-care (expected SCHFI mean score equal to or greater than 70). Maintenance scores were an average of 54.27 (95% CI, 47.40-61.14; $P < .001$), whereas symptom perception and management scores had even lower averages: 49.75 (95% CI, 40.75-58.75; $P < .001$) and 41.36 (95% CI, 33.62-49.12; $P < .001$), respectively. On average, the sample scored highest on their confidence to manage symptoms (mean, 57.45); however, scores were still significantly lower than the expected average of 70 (95 CI, 48.34-66.56; $P = .009$). Despite lower-than-expected SCHFI scores, participants in this sample largely remained out of the hospital (91.2%). (See Table 2.)

Nonparametric approaches indicated similar trends among caregivers. Maintenance scores were significantly lower than the expected average of 70, averaging 37.1 (95% CI, 30.96-44.0; $P = .022$). Both management and confidence scores for caregivers were lower than expected at an average of 25.25 (95% CI, 8.33-40.00; $P = .015$) and 45.24 (95% CI, 34.99-56.66; $P = .022$), respectively. (See Table 3.)

**Research question #3: Behaviors, treatments, and self-management strategies during the pandemic period.** Despite the pandemic disrupting in-person care, many participants reported they’d sustained follow-up with their providers either through telemedicine or phone calls. Most study participants (79.4%) spoke with their healthcare provider during the pandemic period, with over a third (38.0%) using telehealth approaches. Study participants spoke with their clinicians frequently about their HF care needs: an average of 2.9 times in the pandemic period.

### Table 1: Number of admitted patients prepandemic, during the pandemic period, and who avoided readmission

|                         | Prepandemic period: Total number of patients admitted with an HF diagnosis meeting inclusion criteria | Pandemic period: Total number of patients readmitted after February 29, 2020 | Pandemic period: Total number of patients who avoided readmission after February 29, 2020 |
|-------------------------|---------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|
| Number of patients (%)  | 205                                                                                               | 18 (8.8)                                                                      | 187 (91.2)                                                                       |
Study participants self-reported that the strategies they used to avoid readmission were driven by their fear of contracting COVID-19. Self-quarantine and lifestyle changes were the two main strategies reported. Specifically, 17.2% of the sample reported that they didn’t go out to eat and were eating healthier at home, and 24.1% reported they monitored their salt intake. Additionally, 10% of the sample said that during the pandemic they checked their weight more consistently.

**Discussion**

This study confirmed the reduction in HF readmissions at the authors’ institution during the initial wave of the COVID-19 pandemic. The rate of patients readmitted with HF in the pandemic period (8.8%) was dramatically lower than the health system’s historical trend, which ranges from 15.8% to 19.1% HF readmission rate. This institution’s readmission rate was compared with Centers for Medicare and Medicaid Services readmission data, which reports any all-cause readmission to the same institution or another acute care hospital for the hospital’s HF population. This data supported a reduced readmission rate. According to a recently published study, the average financial cost to hospitals for HF readmissions is $15,618 per patient readmission.24 Based on the results of this study, over $328,500 in projected inpatient acute care costs were saved during the pandemic period. This was calculated using the total number of eligible patients (205) multiplied by the historical high readmission rate (19.1%) multiplied by the average cost of an HF readmission ($15,681) minus the costs associated with the remaining (18) patients in this study who were readmitted.

Study participants identified the encouragement of social distancing and the fear of contracting COVID-19 as the driving force behind the changes in behaviors associated with HF self-care. Although not confident in their own self-care of HF, participants did identify four factors that contributed to their comfort in managing their HF at home and avoiding readmissions: (1) access to their provider both through telemedicine or by telephone; (2) self-isolating practices during which participants didn’t dine outside the home; (3) increased focus on their salt intake as well as diet modification and eating healthier meals; and (4) increasing daily exercise. Study participants indicated that in the pandemic period, they checked their weight more consistently and had better than normal follow-up with their providers. The changes patients

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**Table 2: t test comparing sample SCHFI scores to estimated mean score of 70 used to identify an adequate level of heart failure self-care (n = 29)**

|                      | Mean (SD)   | 95% Confidence Interval | P*   | Effect Size (Cohen d) |
|----------------------|-------------|-------------------------|------|----------------------|
| Maintenance          | 54.27 (15.70) | (47.40, 61.14)          | <.001| 1.01                 |
| Symptom perception   | 49.75 (20.29) | (40.75, 58.75)          | <.001| 0.99                 |
| Management           | 41.36 (17.47) | (33.62, 49.12)          | <.001| 1.64                 |
| Confidence           | 57.45 (20.55) | (48.34, 66.56)          | .009 | 0.61                 |

Scores range from 0 to 100; higher scores indicate better self-care

*Statistical significance set at P< 0.05

**Table 3: Wilcoxon tests comparing sample CCSCHFI scores to estimated mean score of 70 used to identify an adequate level of heart failure self-care (n = 7)**

|                      | Median      | 95% Confidence Interval | P*   | Effect Size (r) |
|----------------------|-------------|-------------------------|------|-----------------|
| Maintenance          | 37.99       | 30.95-44.0              | .022 | 0.896           |
| Symptom perception   | 27.50       | 8.00-40.0               | .015 | 0.994           |
| Management           | 48.55       | 38.99-56.66             | .022 | 0.898           |

Scores range from 0 to 100; higher scores indicate better self-care

*Statistical significance set at P< 0.05
Heart failure readmission reductions during the COVID-19 pandemic

made and the strategies put into place in the pandemic period to raise their level of comfort, in light of their low confidence to self-manage, appeared to have aided in stability of their HF. These findings provide insight into potential strategies nurse leaders can use in the future to support patient comfort in managing their HF at home when their confidence in self-care is low. Strategies include leadership support for telemedicine programming specific to the availability and implementation of telemedicine platforms aimed to support patient/provider communication; dining reinforcement and education regarding dietary needs, limiting dining out when possible and maintaining a healthy diet; and regular daily exercise as tolerated and as able.

Interestingly, the results of the SCHFI and the CCSCHFI indicated that patients and caregivers aren't confident in their HF care. Scores were statistically significantly lower than previously published cut-off scores typically seen among patients with HF who can care for themselves. Findings suggest that confidence in self-care can be effectively augmented with alternate methods for receiving care, such as telemedicine visits. Further, patients' confidence in their self-care was much higher than their caregivers' confidence in caring for them. This highlights the importance of community-based strategies to support not only patients with HF but also their caregivers to mitigate HF readmissions.

Some suggested strategies that will need further exploration for increasing HF self-care confidence include: (1) developing a community-based HF caregiver support group; (2) regular diet and exercise education using a virtual platform; and (3) continuous education regarding symptoms and symptom recognition. Additionally, the use of advanced practice nurses for virtual outreach or home visits that are separate and distinct from the traditional home-care support may be effective in early identification and mitigation of HF symptoms while providing additional supportive education.

Limitations
After analyzing the large sample size identified in the chart review component of this study, few responded to the prospective survey component. As such, the small sample size, although sufficiently powered to detect differences from historical cut-off scores, limits generalizability. Further, no data were available on HF severity and symptom severity. Future prospective research with larger diverse samples using validated patient-reported outcomes and the SCHFI are needed to improve understanding of how patients and caregivers effectively manage HF symptoms at home during the ongoing pandemic. Despite these limitations, this study is among the first to survey patients who successfully managed their HF symptoms and remained out of the hospital during the COVID-19 pandemic.

Leadership implications
Nurse leaders are poised to lead innovative strategies that support patients’ and their caregivers’ ability to manage their HF at home, thus avoiding readmission to the hospital. Findings of this study demonstrate that although patients could avoid readmission for HF, they aren’t confident in their ability to manage their own disease and recognize the symptoms of an exacerbation. Nurse leaders should focus on interventions to enhance confidence in HF self-care and caregiver care to support ongoing readmission reductions. Evaluation of both inpatient education and outpatient/community education offerings is recommended to enhance understanding and confidence in HF self-care. For example, AHA recommendation for the provision of 60 minutes of individualized patient education during inpatient admission is effective.9 Importantly, nurse leaders should explore a multi-professional approach to establishing patient and caregiver support groups within the community along with providing focused education on self-care strategies and symptom recognition and management.

HF management insights
This study adds to the body of research on patients’ self-care of HF as well as the caregiver contribution to HF care during the COVID-19 pandemic. Additionally, this study provides insight into the extent to which patients were comfortable managing their HF symptoms at home and avoiding readmissions despite reporting low confidence. Findings provide guidance for nurse leaders in developing innovative HF self-care programs that support patients in the community with HF, ultimately improving the patients’ quality of life and preventing costly HF readmissions.14
Additional research is needed to evaluate the effectiveness of community-based strategies in increasing patient and caregiver confidence and supporting ongoing readmission reduction.

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