Traci Stewart, RN, MSN, CHFN University of Iowa Hospitals and Clinics Iowa City, IA Self-care abilities in patients with heart failure (HF) are directly related to quality of life and outcomes such as hospitalizations and mortality. Patient education is essential in helping patients gain knowledge and skills to become successful in self-care. As the trajectory of the patient's course changes, the HF team members identify barriers, help the patient adapt, and work toward desired goals. Communication and shared decisions about prognosis, symptom management, and treatment options require the HF team to connect with patients and have difficult conversations that can be facilitated with palliative care consultations.

## INTRODUCTION

Pulmonary hypertension (PH) associated with left heart disease is the most common cause of PH.<sup>1</sup> PH is a parameter of increased risk and disease progression in patients with heart failure (HF) with reduced and preserved ejection fraction, left-sided valvular, and congenital heart diseases leading to postcapillary PH.<sup>2</sup> HF guideline-directed medical therapy (GDMT) is often the topic of focus; however, nonpharmacological management of HF including attention to self-care, adherence, diet, exercise, and supportive care are complementary components to pharmacological management. The HF multidisciplinary team educates patients on disease process, medication purpose and side effects, and self-care through the continuum of care. Self-care skills in patients with HF are commonly thought of as acts of monitoring of symptoms, weight, diet, and activity. Poor adherence to self-care can lead to hospitalizations and worsened outcomes despite optimal medical management. Knowledge alone is not sufficient for patients to create long-term self-care strategies. Patients with HF require time and ongoing support to develop skills to overcome barriers to effective self-care.<sup>3</sup> Time constraints can make it difficult for health care providers (HCPs) to create conversations around effective ways to improve self-care. This is a review

focused on helping nurse coordinators develop a collaboration with patients to develop self-care management strategies and will also explore tips for patient education and use palliative care to help with support of the patient and caregiver.

# HF SPECIALIZED CARE

Patients should be referred to HF specialists for assistance with disease management and for consideration of advanced cardiac therapies. Triggers for referral include need for inotropes, advancing function classification, end organ dysfunction, persistent reduced ejection fraction, defibrillation shock, hospitalizations, refractory edema, low blood pressure, and down titration of GDMT (acronym I-NEED-HELP).<sup>4</sup> It is essential for the HF team to deliver accurate diagnosis and, through shared decision making, determine the best treatment options as the patient's course progresses. The multidisciplinary HF team supports patients to obtain and titrate medications and devices and monitor response to therapy. The HF team provides social and psychological support and resources, coordination of care for comorbidities, and offers supportive and palliative care. Education for the patient and caregiver is necessary throughout the entire continuum of care, including prognosis, disease state, treatment options, lifestyle changes, and self-care.

Key Words—heart failure, self-care, adherence, self-management, patient education Correspondence: traci-stewart@uiowa.edu Disclosure: T. Stewart has served as an advisor for Actelion/Janssen and Merck.

# Educating HF Patients

The nurse coordinator's primary role includes educating patients about HF selfcare. An effective teacher is engaged and keeps learners interested. When teaching, it is important to be optimistic, nonjudgmental, and apply the material to the patient's specific circumstances while managing time and resources. Assess the patient's readiness to learn and how the patient best receives information. To improve efficiency, consider what the patient already knows and what the patient needs to know without making any assumptions. Establish and set goals and identify what is immediately applicable for the initial information exchange.

It is important not to overteach and remember that most people can store 7 items in short-term memory (±2 items).<sup>5</sup> Storytelling can aid in remembering for the learner because it uses memories and experiences from long-term memory. Using medical terminology instead of plain language is a common mistake made by HCPs when teaching, so be selective with words.6 Use vocabulary and examples that the learner will relate to from life experiences. Educational materials from Internet sources are often written at much higher readability than the recommended fifth- to sixth-grade reading levels and can be a barrier to adherence; therefore, checking readability levels is necessary for handouts and tools provided to patients."

Upon diagnosis, introduce topics of self-care during clinic visits or during inpatient admissions but not at time of discharge. Focus on topics that are most essential to prevent patients from becoming overwhelmed. Plan time for education when it is convenient for the patient, caregiver, and nurse.

Present topics with visual and written materials while verbally reviewing basic skills to allow visual and auditory learners to process knowledge. Ask patients to repeat back certain parts of the instructions to reinforce concepts for those who learn by doing tasks. Handouts with areas for notes and questions can be beneficial for those who remember by taking notes. Materials should be culturally appropriate and reviewed with family and caregivers when possible.<sup>8</sup> It is important to keep the initial information extremely basic while focusing on information necessary for the patient to start immediately after instruction.

Next steps of the education process should include adding more chunks of information and reinforcing information from earlier discussions. Explore how the patient is tracking or applying information to a daily routine during follow-up telemonitoring, medication titration, or blood work reminder phone checks. Quiz patients about daily habits during follow-up appointments and phone calls to identify barriers and identity misunderstandings or forgotten information. It is important to keep information simple and reinforce often.

Create handouts, resource lists, and tip sheets for patients to use and refer to later. It will improve efficiency for the HF team to have checklists and resources to ensure that essential messages are completed and documented for each patient. Guidelines and disease-specific organizations have tip sheets that can be modified for telemonitoring and patient education materials to include nonpharmacological management and self-care skills. (Table 1).<sup>9</sup>

### SELF-CARE CONCEPTS IN HF

Self-care is the foundation of maintaining health and preventing and managing chronic illness.<sup>11</sup> In patients with HF, patients with better self-care have higher quality-of-life scores and lower mortality and readmissions than patients with poor self-care practices.<sup>12</sup> Three concepts of self-care described by Riegel and Dickson<sup>13</sup> include self-care maintenance, symptom perception (monitoring), and self-care management. Self-care maintenance is achieved when patients can consistently log daily weights and keep intake of fluid and sodium levels at recommended levels. Patients recognize the importance of taking medications as prescribed and avoid gaps in treatments. Patients have an exercise regimen and advance activity safely. It can be summarized as treatment adherence and involves the patient, caregivers, and HCPs. Symptom monitoring or symptom perception is the next skill in self-care, where patients recognize changes, then label change, and make note of the change in condition. Finally, self-care management involves action or a response to the identified concern. This could include contacting HCPs for guidance or adjusting diuretics if authorized to take diuretics as needed.

HF readmissions are common and often preventable; therefore, initiatives to prevent readmission include education on medication management as part of self-management skills, focusing on purpose, changes in doses/frequency, and which to start and stop as part of self-care education topics. Medication nonadherence should be assessed during phone calls and during clinic visits to identify potential deviations from prescribed regimens. Deviations may include not refilling, doubling up doses, skipping doses, incorrect intervals, interrupting therapy, or borrowing someone else's medications and may give clues into deterioration in symptoms or unusual side effects.<sup>14</sup>

### **BARRIERS TO SELF-CARE**

Nurse coordinators have opportunities to impact self-care as a patient's course changes to continually help learn new skills and adapt.<sup>15</sup> Understanding barriers to self-care is an important way to identify if resources are needed or skill review is necessary. Barriers can be complex medical or social issues and may require additional resources such as home health nursing, social services, community agencies, and consultations to other services to manage underlying comorbidities.<sup>16</sup> Adherence to self-care can be limited by a patient's perceived lack of effect, poor health literacy, physical impairments, depression, and cognition. Behavior change is necessary to perform self-care

and may be limited by an attachment to the unhealthy behavior, lack of motivation to change, difficulty deciding when to start the healthy behavior, and difficulty in maintaining the healthy behavior over time.<sup>17</sup> Illness-related barriers to self-care include difficulty integrating self-care across other comorbid conditions, not responding promptly to symptoms, and life events that interfere with healthy behaviors. These barriers make it difficult to start and maintain momentum of behaviors that lead to lifestyle changes.

As a patient's condition progresses and medical regimen increases in complexity, it can be more difficult to expend energy to maintain self-care behaviors. Increasing frequency of telemonitoring and implantable monitors can assist HCPs monitor patients more closely by remote capabilities.<sup>18</sup> Desai and Stevenson<sup>19</sup> describe an intense integrated home management regimen involving a multidisciplinary HF team approach to monitor and direct education, social resources, and supportive care to prevent hospitalizations. Breakdowns in communication with patients and caregivers can be barriers to care such as being unable to leave messages, blocked calls, and unreturned missed calls and letters from the HF team. In addition, changes associated with caregiver support, expenses associated with medications, diet, and transportation can impact adherence.

### PALLIATIVE CARE

Finally, palliative care is another essential component of nonpharmacological care for patients with chronic illness and a HF or PH care center. Risk assessment tools such as Seattle Heart Failure Model or PARADIGM Risk of Events and Death in the Contemporary Treatment of HF (PREDICT-HF) help support clinician judgment to estimate prognosis and help HCPs and patients engage in shared decision making.<sup>20</sup> Decisions for timing and types of advanced therapies should be reassessed often and with condition changes or HF hospitalizations.<sup>21</sup> Patients with HF have a high burden of symptoms, are frequently hospitalized, and often have poor prognostic awareness.<sup>22</sup> Palliative care has been shown to improve quality of life, anxiety, depression, and spiritual wellbeing over usual care.23

#### Table 1. HF Self-Care Educational Resources<sup>a</sup>

HF self-care topic	Resources for patients	Resources for nurse coordinators
Concerning HF symptoms	<ul> <li>Symptom tracker (green, yellow, red), HF team contact numbers, follow-up appointments</li> <li>Weight, vital signs log</li> </ul>	<ul> <li>Telemanagement form</li> <li>Developing skills of gathering history and physical by phone</li> <li>Remote monitoring devices</li> </ul>
Daily weights	<ul><li>Scale</li><li>Step by step instructions</li><li>Log sheet or weight tracking app</li></ul>	<ul><li>Telemanagement form</li><li>Remote monitoring devices</li></ul>
Diet goals: Weight management Cardiac cachexia Sodium/fluid intake	<ul> <li>Weight loss tips</li> <li>Tips for calorie dense foods, eating small meals more often, supplements</li> <li>Sodium handout</li> <li>Fluid and thirst tip tool</li> <li>Dining-out guide</li> <li>Dietitian consultation</li> </ul>	<ul> <li>Lists of diet resources</li> <li>Sodium handout</li> <li>Fluid and thirst tip tool</li> <li>Potassium food lists</li> </ul>
Exercise and activity	<ul> <li>Activity tracker, wearables pedometer</li> <li>Intimacy guide</li> <li>Cardiac or pulmonary rehabilitation consultation</li> </ul>	<ul><li>Safe exercise handout</li><li>Intimacy guide</li><li>Wearables/device monitoring</li></ul>
Medications	<ul> <li>Current medication list</li> <li>Recognizing and calling with side effects</li> <li>Pill box, pill packs</li> <li>Alarms, app reminders</li> <li>Copay cards, coupons, grants</li> </ul>	<ul> <li>Treatments for anticipated side effects</li> <li>Safe over-the-counter medication list</li> <li>Med titration tip sheet: slower titration or spacing out 2 vasodilating meds to help get to GDMT</li> <li>Pair follow-up labs with teaching topics</li> </ul>
Mental health: Coping Anxiety Depression	<ul> <li>Conserving energy tips</li> <li>Anxiety app, exercise, yoga</li> <li>Counseling</li> <li>Support group meetings</li> <li>Medication treatments</li> </ul>	<ul> <li>Depression screening tool (PHQ-9)</li> <li>Support group information</li> </ul>
Sleep	<ul> <li>Reporting symptoms related to HF (orthopnea, paroxysmal nocturnal dyspnea)</li> <li>Sleep tracker/relaxation app</li> <li>Sleep hygiene tip sheet</li> </ul>	<ul> <li>Screening tool for sleep apnea (Epworth sleepiness scale, STOP-Bang)</li> </ul>
Substance avoidance	<ul> <li>Smoking/vaping cessation aids</li> <li>Limiting alcohol</li> <li>Counseling/substance abuse rehabilitation</li> <li>Caution/avoidance list for herbal and over the counter medications</li> </ul>	<ul> <li>Potassium food list</li> <li>Referral sources for substance abuse counseling/rehabilitation</li> <li>Suicide hotline info accessible</li> <li>Safe over-the-counter medication list</li> </ul>
Travel	<ul><li>Travel tip sheet</li><li>Sodium handout</li><li>Dining-out guide</li><li>Airline oxygen form</li></ul>	<ul> <li>Travel letters templates for security</li> <li>Find a HF treating center at destination</li> </ul>
Vaccinations and wellness	<ul> <li>Instruction to get respiratory vaccines as indicated</li> <li>Handwashing tips to avoid illness</li> <li>Dental consultation</li> </ul>	<ul> <li>Vaccine documentation</li> <li>Safe over-the-counter medication list</li> </ul>
Supportive care	<ul> <li>Advanced directives handouts/forms</li> <li>Medical durable power of attorney document</li> <li>Living will document</li> <li>Physician orders for scope of treatment document</li> <li>Palliative care consultation</li> <li>Hospice referral</li> </ul>	<ul> <li>Kansas City Cardiomyopathy Questionnaire</li> <li>Risk assessment tools</li> <li>REMAP stepwise approach to goals of care discussion<sup>10</sup></li> <li>Goals of care documentation form</li> <li>NURSE acronym for dealing with strong emotions<sup>10</sup></li> <li>Serious illness conversation guide</li> <li>Physician orders for scope of treatment form</li> </ul>

Abbreviations: GDMT, guideline-directed medical therapy; HF, heart failure; STOP-Bang, Snore, Tired, Observed, Pressure, Body mass index, Age, Neck size, Gender; REMAP, REframe, Map, Align, Plan; NURSE, Naming, Understanding, Respecting, Supporting, Exploring.

<sup>a</sup>Create materials for patients or use existing materials from HF guidelines, organizations, or colleagues. Explore more at: American Association of Heart Failure Nurses-Patient Education, Heart Failure Society of America-Patient Education, American Heart Association-Get with the Guidelines, Pulmonary Hypertension Association-Patients, Living with PH.

Since the trajectory of each patient is different, timing of a formal referral to palliative care should be early and increase in frequency of interactions as disease progresses. Common triggers for referral include worsening symptoms, functional decline, hospitalization, increase in diuretic, hypotension, or decline in renal function. Areas of management include physical and psychological symptom management, goals of care in complex medical decisions, advanced care planning, and caregiving support.<sup>24</sup> HF team members become skilled at discussing symptom burden and disease progression; however, goals of care and advanced care planning are less likely to be discussed.<sup>25</sup> Often, patients want HCPs to initiate discussions about disease progression, but HCP are reluctant to initiate discussions due to concerns of causing patient anxiety.<sup>26</sup> A discrepancy in approaching sensitive topics can make a palliative care consultation appreciated by patients and HCPs. Primary palliative care may be best initiated by providers with established relationships with patients to identify values, goals, and preferred treatments. Palliative care specialists have expertise in more difficult conversations can collaborate with the HF team, patient, and family for more challenging needs and discussions. Palliative care tools such as the serious illness conversation guide and practice by role play sessions have been shown to improve effective communication.<sup>27</sup> The benefits of palliative care early in the patient's course can improve quality of life and prevent suffering.<sup>16</sup>

### CONCLUSION

The nonpharmacological aspects of HF management are the focus of HF nurse coordinators. Working with patients to educate, set goals, change behaviors, identify barriers, and achieve self-management is a continual process. Along with the HF team and palliative care clinicians, nurses serve as a direct link between the patient's treatment plan and outcome.

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