

Pilot Implementation of a Low-Literacy Zone Tool for Heart Failure Self-management

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Heart failure affects 6.5 million Americans, with 1 million hospitalizations annually, a 22% readmission rate, and \$31 billion in health care costs. Palliative care decreases symptom burden, readmissions, and costs. Many elderly patients have difficulty recognizing and reporting heart failure symptoms to their providers in a timely manner. Self-management tools with color-coded zones (green = "all clear," yellow = "caution," red = "take action") help patients recognize and respond to heart failure symptoms and reduce readmissions. The purpose of this quality improvement project was to develop, implement, and evaluate a low-literacy zone tool for heart failure self-management with home-based palliative care patients. An interdisciplinary palliative care team developed this zone tool. Health literacy was prescreened with the Newest Vital Sign instrument. Nurses provided the zone tool to patients and caregivers and instructed them in use of this tool for daily self-monitoring. In postimplementation surveys, participants rated the zone tool as easy to understand and helpful in recognizing and reporting symptoms. This project demonstrated feasibility of a new zone tool for heart failure self-management, resulting in a practice change for this home-based palliative care program. The interdisciplinary team eventually developed similar zone tools for cancer, cirrhosis, chronic obstructive pulmonary disease, dementia, and frailty self-management.

KEY WORDS

heart failure, low-literacy, palliative care, self-management, zone tool

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eart failure (HF) is a progressive, chronic illness in which the heart muscle is unable to pump enough blood to meet the body's needs for blood and oxygen. Signs and symptoms of HF include shortness of breath (particularly with exertion or lying supine), edema in legs or abdomen, weight gain, cough, fatigue, and loss of appetite. For patients with end-stage HF, the most commonly reported symptoms are dry mouth, lack of energy, and shortness of breath.

Heart failure affects an estimated 6.5 million people with nearly 1 million new cases diagnosed annually. The number of Americans with HF is projected to increase to more than 8 million people by the year 2030. Each year, HF causes 1 million hospitalizations, costs nearly \$31 billion in health care expenditures, and contributes to more than 75 000 deaths. The most recently available Medicare national 30-day readmission rate for HF is 22%. Although HF has a 5-year mortality rate of nearly 50%, most patients with advanced HF do not understand the severity or terminality of this condition.

Palliative care (PC) helps decrease symptom burden and enhance quality of life (QoL) in HF patients.⁸ Interdisciplinary community-based PC teams help patients clarify their goals of care and proactively manage advanced illnesses in their place of residence.^{9,10} Home-based PC for HF patients decreases emergency room visits, all-cause hospital readmissions, and HF readmissions, resulting in significant cost savings.⁸⁻¹²

When patients or their caregivers recognize and promptly report signs and symptoms of early HF exacerbations, they can avoid hospitalization, decrease symptom burden, and improve their QoL. ¹³ Many elderly HF patients in need of medical attention do not contact their providers in a timely manner because of lack of knowledge and/or failure to recognize early warning signs of HF exacerbation. ¹⁴ Therefore, elderly patients with advanced HF and their caregivers need education and decision-support tools to facilitate prompt symptom recognition and reporting.

Decision-support tools with color-coded zones rank symptoms in degree of severity: green = minimal or mild symptoms (condition stable), yellow = moderate symptoms (early exacerbation), red = severe symptoms (advanced exacerbation). Zone tools (also known as stoplight tools) are used for self-care education and support to help patients with a variety of chronic conditions, such as asthma,



diabetes, and HF.^{15,16} Zone tools are designed to help patients and caregivers recognize signs and symptoms of an exacerbation and take timely appropriate actions, which makes these tools well suited for use in homebased PC.¹⁶

Several examples of HF zone tools are available online. ¹⁵⁻¹⁷ Interventions that incorporate the use of HF zone tools can decrease readmissions and deaths. ¹⁸⁻²⁰ The purpose of this quality improvement (QI) project was to develop, implement, and evaluate a low-literacy zone tool for HF self-management for home-based PC patients and their caregivers.

LITERATURE REVIEW

To manage advanced HF symptoms effectively at home and avoid hospitalization, patients must be engaged in self-management (also known as self-care). Health care providers help patients practice HF self-management by providing information on appropriate diet, medications, exercise, and self-monitoring for HF signs and symptoms. ²¹ Improved HF self-management reduces hospitalizations, lowers HF inpatient costs, and improves OoL. ^{21,22}

Factors that facilitate HF self-management are the ability to recognize and respond appropriately to early HF symptoms, deliberate behavior change, family support, improved systems of care, and care coordination in transitions across settings. Heart failure self-management is also enhanced by education and telemonitoring to augment symptom recognition and by patients' perception that their providers are responsive and interested in their needs and share information well with them. Heart factors that adversely impact HF self-management include age-related symptoms, social issues, and cognitive impairment, poor patient-provider communication, and lack of provider continuity, untiple comorbidities, cultural beliefs about HF, and social norms.

Hospice and PC nurses work with HF patients and their caregivers to facilitate self-management and mitigate factors that interfere with self-management. Caregivers can enhance patients' HF self-management through concrete activities, such as weighing patients, and interpersonal activities, such as facilitating understanding of self-care needs. ²⁷ Caregivers' HF-related knowledge and patient-caregiver agreement on who is providing HF care positively impact caregiver engagement in HF self-care maintenance. ²⁸

The influence of health literacy (HL) on HF outcomes including self-management is receiving increased attention. ²⁹⁻³¹ Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." ³² Low HL is associated with adverse self-management behaviors, decreased knowledge of one's health condition, poor medication

recall, low adherence to treatment plans, decreased physical and mental health, increased rates of hospitalization and mortality, and poor HF-related QoL.³³

Zone tools were developed in part to address the deleterious effects of low HL on health outcomes. ³⁴ Zone tools employ the use of green-yellow-red graphics and simple language to mitigate the influence of low HL on self-management behaviors. The green-yellow-red zones in these self-management tools also help patients and/or caregivers recognize and respond appropriately to signs and symptoms of chronic disease exacerbations. Research suggests that interventions incorporating the use of HF zone tools may decrease hospitalizations ¹⁸⁻²⁰ and mortality, ^{18,19} improve symptom recognition and monitoring, ^{18,35} and improve QoL, ¹⁹ which are all key objectives of most PC programs.

METHODS

The theoretical framework for this project was the Situation-Specific Theory of Heart Failure Self-care. ³⁶ The authors of this theory identified 3 essential self-care processes. Maintenance denotes treatment adherence and healthy behaviors, such as taking medications, exercising, and following a lowsodium diet. Symptom perception involves detection and interpretation of physical sensations through body listening, monitoring signs, and recognizing, interpreting, and labeling symptoms of HF. Management represents the person's response to symptoms, such as contacting a health care provider and evaluating treatment. Symptom perception mediates the relationship between self-care maintenance and self-care management. The theory's authors also acknowledge that because of their functional limitations, many HF patients require caregivers' assistance with these 3 self-care processes. The HF zone tool developed for this project was designed to facilitate self-care maintenance, symptom perception, and management by PC patients and their caregivers.

Setting

The QI project was implemented in a hospice's home-based PC program within a large nonprofit health system in southern California. The program's interdisciplinary team of nurses, social workers, and physicians works together to educate patients and caregivers on disease process, symptom recognition, diet, and medication management. Team members also coordinate care with patients' primary care and specialty providers. The PC team helps patients and caregivers develop long-term plans of care aligned with their values and facilitate a smooth transfer to hospice care when appropriate. This PC program has significantly decreased emergency department visits, hospitalizations, and costs of care among patients with advanced HF, chronic obstructive pulmonary disease, cancer, and/or dementia. 10,11



The program achieved Joint Commission certification in Community-Based Palliative Care in 2018 and was awarded the 2019 Hearst Health Prize for excellence in population health.³⁷

Patients receive weekly or biweekly home visits in the first 2 months after admission and then monthly or bimonthly nursing visits thereafter, with follow-up phone calls between visits. The program offers 24/7 nursing phone support via the hospice's call center. During a typical home visit, the nurse obtains an interim history of patients' symptoms, performs a brief physical assessment, and educates patients and caregivers about managing their symptoms, diet, medications, and activity. The nurse also instructs patients/caregivers about the natural progression of their advanced chronic illness(es) and contacts the physician for significant changes in the patient's condition that may require a medication change of medication or treatment. All HF patients/caregivers receive a booklet titled A Guide for People With Heart Failure, 38 which nurses use to teach them about HF symptoms, diet, medication, and strategies for managing this condition at home.

Project Development

The interdisciplinary team developed a new low-literacy zone tool for HF self-management (Figure 1) geared toward elderly HF patients. Prior to developing and implementing this zone tool, the program provided patients a printed handout titled "Know When to Call Your Nurse." That handout simply listed signs and symptoms of HF exacerbation with instructions on how to contact the nurse, but did not differentiate HF symptoms based on their severity. The new zone tool was developed as a practice change to replace the previous HF patient handout and facilitate patient/caregiver recognition and reporting of symptoms of HF exacerbation.

The new HF zone tool's format was loosely adapted from the "Congestive Heart Failure Zones for Management" tool found in early 2016 on the Visiting Nurse Associations of America Blueprint for Excellence website. ³⁹ The lead author learned via email correspondence with the Visiting Nurse Associations of America that this zone tool on their website was in the public domain. The interdisciplinary team worked together to tailor the HF zone tool's content for this home-based PC program's patients and their caregivers.

The PC team decided to focus symptom management on weight, edema, dyspnea, and fatigue. Each symptom was grouped into green, yellow, and red zones based on severity. To meet the needs of lower-literacy patients and caregivers, the team used simple words and short phrases in the HF zone tool to achieve a second-grade reading level, per the Readability feature in Microsoft Word's Spelling and Grammar function. ⁴⁰ The team also created a self-monitoring chart (Figure 2) as a companion

to the new HF zone tool for patients to record their weight and severity of edema, dyspnea, and fatigue daily.

Since this project focused on implementing and evaluating a low-literacy HF zone tool, the authors decided to use the Newest Vital Sign (NVS) instrument ⁴¹ to prescreen for HL. This widely used tool features 6 questions based on a nutrition content label for a fictitious type of ice cream. The NVS measures the ability to read, understand, and analyze words (prose literacy), numbers (numeracy), and forms (document literacy). ⁴² On the NVS, a score of 0 to 1 suggests high likelihood (≥50%) of limited HL; a score of 2 to 3 indicates the possibility of limited HL, and a score of 4 to 6 almost always indicates adequate HL.

To evaluate the effectiveness of the new HF zone tool, the lead author developed a feasibility survey and provided in-service training for nurses. The survey asked participants to rate (on a 1- to 5-point Likert scale) the zone tool's ease of reading and helpfulness for recognizing and responding to their HF symptoms. Three open-ended questions elicited patient and caregiver subjective feedback and suggestions for improving the project process. A survey with similar Likert-type and open-ended questions was developed to assess participating nurses' impressions of the new zone tool and perspectives on participating in this project. The training session for nurses assisting with the project explained use of the NVS instrument, the new HF zone tool, and the feasibility survey.

Implementation

Eight HF patients (5 females, 3 males) and/or their caregivers participated in this QI project over a 3-month period. Patients' average age was 85 years, and their length of stay on the PC program averaged 4.3 months. Of the 8 patients, 4 were white, 2 were Asian, 1 was African American, and 1 was Hispanic. Five patients had full-time caregivers, 1 had a part-time caregiver, and 2 had no caregiver. Caregivers' ages and demographic information were not collected.

The lead author and 2 nurse colleagues in the PC program implemented the new HF zone tool intervention over a 3-month pilot period. The nurses prescreened participants' HL using the NVS to ensure the patient or caregiver would be able to understand and use the HF zone tool. Seven of the 8 participating patients or caregivers had adequate HL. One patient had a high possibility of low HL, so the caregiver was invited and agreed to participate on behalf of this patient. Four patients with adequate HL asked their caregivers to participate with them or on their behalf. Three other patients with adequate HL participated on their own behalf.

The nurses then provided the new HF zone tool (Figure 1) and companion chart (Figure 2) to the patients and/or caregivers and explained how to use this tool and companion chart for daily self-monitoring. Nurses instructed patients/caregivers to determine in which color zone their symptoms were and how to use the zone tool for self-care management.

FEELING?

10W ARE YOU

8

Symptom Management Series

HEART FAILURE - ZONES FOR SELF MANAGEMENT

Green Zone: All Clear

- · Your usual weight:
- · Trouble breathing during activity
- Little or no swelling in feet, ankles or legs. Little or no swelling in belly
- Little or no tiredness during normal activities



Your symptoms are under control

- Record weight every morning
- · Continue medications as ordered
- Keep activity as tolerated
- Follow low salt diet as instructed by nurse/doctor
- Monitor symptoms daily and note any changes

Yellow Zone: Caution

- Weight gain of 2 lbs. in 1 day or weight gain of 4 lbs. in 1 week or less
- · More trouble breathing than usual
- More swelling in feet, ankles or legs. More swelling or bloating in belly
- More tiredness than usual (at rest or with activities)

You may also have:

- More coughing or wheezing
- Some chest pain with activity



Your symptoms are increasing or getting worse

- Call your Transitions nurse EARLY in the day or when symptoms increase 619-667-1900
- You may need a change in your medications

Red Zone: Medical Alert

- •Weight gain of 5 or more lbs. in 1-2 days
- •Severe trouble breathing (at rest or with little activity)
- Severe swelling in feet, ankles or legs (may include leg drainage) or severe bloating in belly
- Very tired and unable to do most activities

You may also have:

- Severe coughing, wheezing or chest tightness
- Severe chest pain



Your symptoms are becoming severe or much worse

- Call your Transitions nurse immediately 619- 667-1900 or call your doctor
- You need to be evaluated by your nurse or doctor <u>TODAY!</u>

Adapted with permission from VNAA Blueprint for Excellence



FIGURE 1. Sharp Transitions original heart failure zone tool used in quality improvement project.

When patients' HF symptoms were stable (absent or mild), they were in the "Green Zone: All Clear" and were advised to continue monitoring weight and symptoms daily, maintain a low-sodium diet, take HF medications as ordered, and perform physical activity as tolerated. When their HF

symptoms were moderately increased, patients were in the "Yellow Zone: Caution" and advised to contact the PC nurse, who provided strategies to relieve symptoms by phone and then followed up with a home visit. When patients' symptoms were more severe, they were in the "Red



Transitions Program 619-667-1900

Heart Failure Zones for Self-management Daily Self-checkup

Month: Date:	Weight (Amount gained or lost in past day/week)	Swelling in Feet, Ankles, Legs (none, little, more than usual, severe)	Trouble Breathing at rest or with activity (none, little, more than usual, severe)	Tiredness (none, little, more than usual, severe)	Zone: (Green, Yellow, Red)
1					
2					
3					
4					
5					
6					
7					

FIGURE 2. Daily heart failure self-monitoring chart (companion to heart failure zone tool).



Zone: Medical Alert" and instructed to call the nurse immediately, so the nurse could make an unscheduled visit to help patients manage severe symptoms at home and avoid an emergency room visit or hospitalization, if possible. The nurses reviewed the HF zone tool instructions and the self-monitoring chart with patients/caregivers at each follow-up visit during this pilot project.

RESULTS

Project Evaluation

Two months after initially providing the HF zone tool, the nurses asked patients or caregivers to complete the author-developed feasibility survey, which all 8 participants did complete. In response to the Likert-scale items on this survey, patients/caregivers rated the zone tool as "somewhat easy to understand" (average score of 4.0 on a 1- to 5-point scale) and midway between "somewhat helpful" and "very helpful" (average score of 4.43 on a 1- to 5-point scale) in enabling them to recognize signs and symptoms of HF exacerbation. In response to the survey's open-ended questions, multiple patients/caregivers reported that

participating in the project helped them be more aware of their HF and their health and that the zone tool helped them recognize the signs and symptoms of HF exacerbation. Patients/caregivers disliked taking time to complete the daily self-monitoring chart and lack of space on the daily self-monitoring form to record patient's blood pressure and pulse. Suggestions for improvement were to simplify the self-monitoring form and add columns to record pulse and blood pressure.

The 2 nurses involved with implementing the project provided feedback via a similar author-developed feasibility survey. Both nurses found the tool "somewhat helpful." One nurse rated the zone tool's readability as "very easy to understand," and the other rated it "somewhat hard to understand." In response to the open-ended questions, the 2 nurses noted that the new HF zone tool helped their patients learn about and understand which signs and symptoms of HF needed to be reported to the nurse. The nurses also recommended further simplification of the language in the HF zone tool to facilitate greater understanding of HF self-management for a lower-literacy population.

HEART FAILURE - ZONES FOR SELF MANAGEMENT

Green Zone: All Clear NO CHANGE IN: · Your usual weight: · Breathing, coughing or wheezing · Swelling 10W ARE YOU FEELING? · Physical abilities · Sleeping patterns Appetite · Medications NO: Falls, slips or injuries New chest pains Symptoms and/or behaviors are well managed · Record weight every morning · Continue medications as ordered · Keep activity as tolerated · Follow low salt diet as instructed by nurse/doctor Monitor symptoms daily and note any changes

Yellow Zone: Caution

MORE:

- · Weight gain:
- 2 lbs. in 1 day or -
- 4 lbs. in 1 week or less
- Trouble breathing, coughing or wheezing
- Swelling (especially in feet, ankles, legs, or belly)
- Tiredness than usual (at rest or with activities)

CHANGE IN:

- Physical abilities
- Sleeping Pattern
- Appetite

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ANV:

- Chest pain with activity
- · New chest pain
- Medication changes

Symptoms and/or behaviors are increasing or getting worse

- Call your Transitions nurse EARLY in the day or when symptoms increase 619-667-1900
- You may need a change in your medications

Red Zone: Medical Alert

MUCH MORE:

- Weight gain:
- 5 or more lbs. in 1-2 days
- Trouble breathing, coughing or wheezing (at rest or with little activity)
- Swelling in feet, ankles or legs (may include leg drainage) or bloating in belly
- Weakness
- Sleeping or interrupted sleep

CHANGE IN:

- Physical abilities
- Appetite

ANY:

- Severe chest pain
- Falls, slips or injuries



Symptoms and/or behaviors are becoming severe or much worse

- Call your Transitions nurse immediately 619-667-1900 or call your doctor
- You need to be evaluated by your nurse or doctor TODAY!

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Project Limitations

This QI project was limited by the small number of participants who utilized and evaluated the new HF zone tool. This was mostly due to the brief implementation period (approximately 3 months) and small number of nurses who assisted the lead author with the project implementation. A longer implementation period and additional nurses would have enabled a greater number of patients/caregivers to participate in using and evaluating the new HF zone tool. Additional questions on the postimplementation surveys could also have provided more detailed evaluations by participants and nurses.

DISCUSSION

This QI project developed, implemented, and evaluated a low-literacy zone tool for self-management for patients with advanced HF in a home-based PC program. Postimplementation feedback via feasibility surveys from patients and caregivers indicated that with 1 exception the zone tool was easy to read and understand. Participants and nurses also indicated in the feasibility surveys that the new zone tool helped them recognize the signs/symptoms of HF exacerbation to report to the nurse. Based on the nurses' feedback, the PC team further simplified the language of the original HF zone tool in a revised tool (Figure 3) to facilitate greater understanding of the 3 color-coded zones of HF symptom severity. Pilot implementation of the zone tool for HF self-management thus led to a practice change in which the PC team began using the zone tool as the new standard of care for helping patients and caregivers better manage HF in the home setting.

FURTHER IMPLICATIONS FOR PRACTICE

After completing this pilot project, the PC team decided to develop and implement similar low-literacy zone tools for self-management of 5 other advanced chronic illnesses (chronic obstructive pulmonary disease, dementia, frailty, cancer, and cirrhosis). Thus, the low-literacy zone tool for heart failure self-management initially developed by the interdisciplinary team eventually became the prototype for a series of disease-specific zone tools developed and implemented in this PC program. The team's nurses are using these decision-support tools to help educate all patients/caregivers in recognizing and reporting symptoms of exacerbations for these advanced chronic conditions. Future projects could evaluate these tools' effectiveness in improving home-based palliative management of advanced chronic illnesses.

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