

Understanding the Needs of Congestive Heart Failure Patients

Creating Value for Patients: Meeting Needs and Reducing Suffering

All patients' needs are not the same. Some groups of patients—whether segmented by clinical condition, patient demographic or some other criteria—are better served by current care delivery models than others. Purposeful segmenting of health care data offers new perspectives on care by focusing on outcomes for condition-specific patient populations thus improving health care professionals' understanding of met and unmet needs for distinct groups. These insights enhance the ability to identify opportunities to re-design care around the needs of the patient in support of efforts to reduce patient suffering, improve clinical health, and provide impactful education and empathy.

This brief describes the met and unmet needs of Congestive Heart Failure (CHF) patients based on national findings. Further, it places these findings within the context of a discussion of what it is like to have CHF and be a patient with CHF. The purpose is to identify opportunities for improving care and to enhance staff empathy by discussing the care process from the patient point of view.

What Should We Know About CHF?

People who suffer from heart failure (HF) have a heart that is less effective at pumping blood than normal. Conditions such as cardiovascular disease (CVD) and hypertension (HTN) weaken or stiffen the heart decreasing its ability to maintain adequate blood flow through the body. The heart muscle compensates by stretching or thickening to increase the cardiac output, helping in the short term, but weakening the heart muscle over time from the extra exertion required. The kidneys are next to respond by retaining fluid and sodium to increase circulatory volume and maintain blood pressure. When this fluid builds up in the extremities, lungs, or other organs the body is said to be congested. Maintaining a healthy fluid balance is essential for life. In HF patients this requires diligence and persistence

Fatigue and shortness of breath are common symptoms of congestive heart failure (CHF). These symptoms occur with exertion in early stages; as the disease progresses, patients experience these symptoms at rest. Edema can become severe as fluid retention worsens in the later stages of the disease. Significant liver congestion may result in impaired liver function, jaundice, and even coagulopathy. Breathing becomes difficult when lying flat and patients have to sleep sitting up. Frequent trips to the bathroom during the night due to diuretic therapy or naturally occurring fluid shifts also interrupt healthy sleep patterns. Sleep deprivation, chronic fatigue, activity intolerance due to shortness of breath, and a daily focus on disease all contribute to a perceived lower quality of life.

Treatment varies depending on the underlying cause, and severity of symptoms. In people with stable, mild HF physicians commonly prescribe lifestyle modifications—such as smoking cessation, physical exercise, and dietary changes. Standard pharmacologic interventions in the early stages include diuretics, angiotensin converting enzyme inhibitors or angiotensin receptor blockers, and beta blockers. As the disease progresses aldosterone antagonists, or hydralazine plus a nitrate may be used. Sometimes, depending on the cause and severity, an implanted pacemaker or cardiac defibrillator may be recommended. Patients with advanced stages of the disease may also face decisions about cardiac resynchronization therapy, cardiac contractility modulation, or a ventricular assistive device.

Who are These Patients? What is it like to be a Patient with CHF?

It is estimated that 5.8 million people in the United States have CHF resulting in one million hospitalizations annually, costing approximately \$32 billion dollars and contributing to one in nine deaths. 14% of Medicare beneficiaries carry a diagnosis of CHF yet this Diagnosis Related Grouping (DRG) accounts for 43% of Medicare Part A and B spending (Dall, Blanchard, Gallo, & Semilla, 2015). This disease affects men and women equally, however the rate of hospitalization for CHF is highest among African Americans, followed by Hispanics, Native Americans, and whites respectively. Additionally, acute care CHF patients age sixty-five and older are more likely to spend time in a rehabilitation setting before being discharged home as compared to patients with CHF who are under age sixty-five.

According to the AHA 24% of discharged HF patients are readmitted within thirty days, and if the time frame is expanded to sixty days that number jumps to 50%. Some readmissions are attributable to clinical comorbidities; however, the availability of resources to address functional status, quality of life, and limitations on adherence with care are also identified as contributors to readmission of these patients (Desai & Stevenson, 2012). These predictors may be more mendable with attention to individual need.

When a person receives a diagnosis of CHF they are faced with the fact that their health will steadily decline. Concerns, fears and disappointments arise from patients' realization that the patient requires routine medical attention going forward, has a shortened life expectancy, and often must make major lifestyle changes such as abandoning favorite foods and activities. Patients on diuretics worry about bathroom availability and may skip doses in order to attend events or do the grocery shopping. Increasing episodes and severity of shortness of breath and periodic chest pain causes distress and anxiety.

CHF symptoms can also have a negative effect on body image and a person's ability to engage in preferred recreational activities—e.g., peripheral edema may be perceived as ugly, a nagging cough can feel disruptive and draw unwanted attention, and dyspnea may prevent a person from daily activities.

As the disease progresses treatment options become more sophisticated and complex. Decisions can become more difficult due to the weariness experienced by those battling chronic disease and the negative cognitive effects of polypharmacy—Digoxin (prescribed to strengthen the pumping action of the heart) for example may cause anxiety or depression, Lisinopril (prescribed to decrease blood pressure and strengthen heart muscle) may cause confusion, and Lopressor (prescribed to control blood pressure, slow the heart rate and improve contractility) can increase irritability and nervousness.

Research: Meeting the Needs of CHF Patients During Acute Inpatient Care

Methodology: A national sample of CHF patients was identified in order to understand their needs and the extent to which current models of care meet those needs. Patients were identified as having CHF based on their primary DRG. As a result, the sample did not include patients with a known history of CHF if they were admitted for another reason (e.g., stroke, hip fracture, GI bleed). A sample of 27,990 admissions for CHF was identified from among a set off 1,539,377 patients who returned an inpatient survey that included HCAHPS questions during the course of 2013.

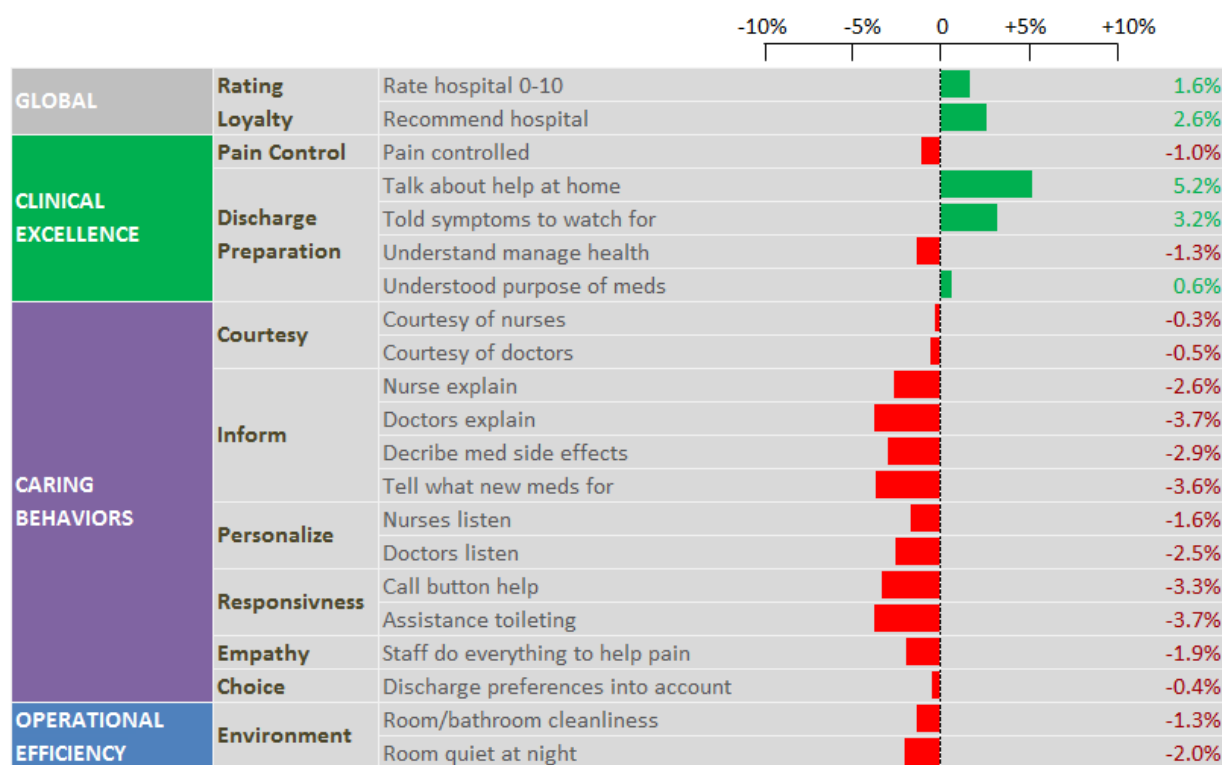
CHF patients evaluations were benchmarked against patients whose reason for admission was defined as 'Medical' based on HCAHPS criteria. The HCAHPS program groups uses primary DRG to categorize patients into three mutually exclusive segments: maternity, surgical and medical. The Medical group was selected for comparison because past research has shown that evaluations of care differ between medically treated and surgically treated patients. Patients in the Medical segment report lower evaluations for some measures of hospital care (O'Malley, Zaslavsky, Elliott, Zaborski, & Cleary, 2005),

perhaps because their care reflects chronic conditions with a greater likelihood of co-morbidities. Further, medically treated patients are more likely to self-report their own health as very poor or poor (Institute for Innovation Findings, 2015) as compared to patients who are admitted for a surgical condition. Prior research (Mylod, 2015) has shown that patient self-report of health is correlated with evaluations of hospital care suggesting that those who report poorer health tend to evaluate hospital experiences less favorably.

Approach: HCAHPS survey items (Table 1) are grouped within the Press Ganey Compassionate Connected Care framework. Individual measures are organized based upon the underlying patient need that is being measured—e.g., a need for information, a need for pain control, or a need for responsiveness (Press Ganey, 2014). Patient needs are further organized based upon the Compassionate Connected Care components of action (Dempsey, Wojciechowski, McConville, & Drain, 2014)—Clinical Excellence, Caring Behaviors, and Operational Excellence—and global ratings. The purpose of these groupings is to visualize the broad themes of care and the patterns of meeting CHF patient needs within and across those topics.

When comparing CHF patients to the larger group of all Medically treated patients, bars that extend to the right (in green) represent attributes of the experience for which CHF patients are more favorable in their evaluations of care than the average medically treated patient. Conversely, when bars extend to the left (in red), CHF patient ratings are less favorable than the average medically treated patient. The length of bars represents the actual difference in the percent of patients who would give a top box response (e.g., ‘Always’, ‘Definitely Yes’, ‘9 or 10’) on each of the HCAHPS measures.

Table 1: Difference in HCAHPS Top Box Scores- CHF Patients vs. Medically Treated Patients



Results: CHF patients are more favorable about their hospital stay, with regard to Global evaluations of care. That is, they are more likely to rate the hospital as a 9 or a 10 (+1.6%) or to state that they would 'Definitely Yes' (+2.6%) recommend their care even though they have a complex, chronic, progressive disease, are in worse health, and more likely to be admitted via the ED than the average medically treated patient. Another area where CHF patients report better than average experiences is within discharge planning and preparation. CHF patients are more likely to report they were asked about the help they would need when they left the hospital (+5.2%), more likely to say they were told what symptoms and issues to watch for (+3.2%) and more likely to understand the purpose for taking their medications at home (+0.6%). However, they are less likely to feel that they know how to manage their own health following discharge (-1.3%).

However, when looking further into different elements of care, that positive benefit is not seen. For other elements of care, the results show lower evaluations of care for patients with CHF as compared to the medically treated acute care population. The relative difference between CHF and the comparison group can help inform which needs are less well met. For example, provision of information poses a greater opportunity to enhance care for CHF patients. Explanations from nurses (-2.6%) and doctors (-3.7%) and information about side effects (-2.9%) and what new medications were for (-3.6%) show the largest negative gaps when comparing CHF to other medically treated patients.

The next largest opportunities are: being responsive during care through timely response to the call button (-3.3%) and providing needed assistance with toileting (-3.7) and personalizing care through the manner in which listening is displayed by nurses (-1.6%) and doctors (-2.5%). Additional areas of opportunity are seen based on patients' evaluation of pain control (-1.0%), empathy shown when addressing pain (-1.9%) and the physical environment of cleanliness (-1.3%) and quiet at night (-2.0%).

Opportunities for Care Redesign: Voices from the Field

The national findings regarding CHF patients were brought to two Subject Matter Expert work groups within the Institute for Innovation. The Drivers of Variation work group focused primarily on discussing potential causes and drivers of patient experience outcomes. The Inventory of Best Practices work group focused primarily on new and innovative ways to enhance care for patients. These two groups each met individually to discuss the patterns of findings for the CHF patient group. The Drivers of Variation team was asked to create a narrative regarding what it was like to be a CHF patient, what it was like to care for a CHF patient and to then hypothesize what might be causing a lack of fit between patient needs and their experiences in the current environment today. Those ideas were captured and summarized and shared with the Inventory of Best Practices group who then suggested ideas for enhancing care that could address the specific issues raised. A synthesis of the work of these two subject matter expert groups is provided in table 2.

Table 2: Understanding and Responding to the Unique Needs of CHF Patients

What do CHF patients experience?	How can we better meet their needs?
CLINICAL EXCELLENCE	
Pain Control	
<p>Why might CHF patients have sub-optimal pain control?</p> <ul style="list-style-type: none"> • Pain may go unaddressed in medically treated CHF patients because, unlike the post-surgical patient, they are not expected to be in pain. However, CHF patients do experience pain and discomfort. • We are less likely to focus on setting goals for managing pain when it's not post-surgical. We need to understand what type of pain CHF patients are experiencing and what the patient goals are. • As a progressive disease, discomfort increases as time goes on. Edema in the extremities can be very uncomfortable. Weeping serous fluid irritates the skin. Shortness of breath causes significant distress and anxiety. Clinicians may not interpret these symptoms as painful but they create serious discomfort. 	<p>How can we better address pain and discomfort among CHF patients?</p> <ul style="list-style-type: none"> ☑ Recognize the experience of CHF patients as being potentially painful. ☑ Remember to ask CHF patients about their pain and discomfort. ☑ Rather than stating, "They are or are not in pain," during shift report we need to pass on information about the discomfort the patient is experiencing. ☑ Remember that for CHF patients, progress to getting well enough to go home can be so slow, but discomfort may persist or intensify throughout their stay. Borrow ideas from acute pain procedures—like a warm blanket—to provide comfort.
Discharge Preparation	
<p>Why are some elements of discharge preparation so favorable for CHF patients?</p> <ul style="list-style-type: none"> • We are focused on reducing readmissions for CHF patients as part of VBP initiatives and therefore talk to the patients about taking medications and help at home. • Patterns of patient evaluations suggest that we have done an effective job working on <i>our needs</i> (to prevent readmission) but still may not fully be meeting <i>their needs</i> (to understand how to manage their illness). We have become skilled at discussing clinical issues relative to this complex progressive disease, but we are not yet addressing the personal side of having a chronic disease. • CHF is a progressive disease and CHF patients are challenged with the responsibility to reliably manage complicated medication regimens which frequent change. Staff cannot rely on a 'brochure' to inform the patient, which is inadequate to really educate the patient. The concept of managing one's own health becomes more difficult with each readmission and subsequent discharge home. 	<p>How can CHF patients be better supported in managing their health?</p> <ul style="list-style-type: none"> ☑ Always assume the patient is a novice and re-cover the same information provided during previous encounters. Repetition beneficial in adult learning especially in times of stress. ☑ Use the discharge instruction protocol as a guide and individualize information shared and the support provided based on patient feedback about needs and concerns. ☑ Provide reminders that this is a progressive disease and patients must be attentive to symptoms and treatment to avoid hospitalization and maintain quality of life.

CARING BEHAVIORS

Inform

Why might CHF patients feel less informed?

- Every hospital visit is not the same just because it is the same person with the same diagnosis. The patient may have prior admissions that are all different from the current experience, creating a conflict between their expectations and present experience.
- Caregivers may become desensitized to CHF patients' need for instruction because it's a chronic illness. We may assume we don't need to explain things because they expect the patient to understand from past experience.
- During an exacerbation physicians and nurses are monitoring for a number of possible scenarios. It is difficult to anticipate how the patient will react to treatment. Clinicians may not be giving clear information about what they expect because they don't exactly know what is coming or because they are waiting for more discussion among clinicians. Patients may feel like they are waiting for an update and not being told what is going on.
- CHF patients are more likely to be an ED or urgent admission. The clinician is focused on stabilizing the patient but may not be directly communicating status and plans. Additionally, patient may be highly stressed and unprepared to take in the information that is offered.
- The patient's basic understanding of the disease process varies greatly. Even those with CHF for years may not have a clear understanding of the disease process.

What can be done to inform CHF patients?

- ☑ During the admission assessment, discuss prior stays and identify what is different this time to gain an understanding of the patient's current needs and expectations.
- ☑ Remember to always act like the patient is a novice and provide teaching and explanations for every patient as if it is their first time.
- ☑ Remember to keep patients informed about their care even as assessments and decisions are being made. Help them understand what is being done, watched for and anticipated.
- ☑ Identify the roles of different clinicians and caregivers and explain the part they play in providing care. Ensure that conversations and consultations are channeled to the patient and family.
- ☑ When patients are admitted through the Emergency Department, take time to review their understanding of the admission decision, the care received and the plan for the inpatient stay.

Responsiveness

Why might CHF patients have concerns about response time and assistance with toileting?

- CHF patients may have enhanced anxiety based on their past or current exacerbation; anxiety can translate into greater fear if someone doesn't show up immediately.
- CHF patients often receive Lasix or other diuretics results in frequent, urgent needs to use the bathroom. Physical reactions to chemical treatments—which can be fairly intensive—may make patients feel a strong need for immediate response.

How can providers improve responsiveness to the needs of CHF patients?

- ☑ Increase the frequency of availability with hourly nursing rounds.
- ☑ Pay deliberate attention to toileting needs to prevent falls and alleviate anxiety associated with not being able to reach a restroom in a timely manner.

Listening

Why would CHF patients not feel that they are being listened to?

- "We listen to what we can fix." When patients have symptoms that we can address we are efficient at responding. But for CHF, care needs can be less concrete than something like 'a 7 out of 10 for pain'. Rather, their symptoms are more nebulous—e.g., they are uncomfortable from low output. We forget to acknowledge the issue they are having, we can't solve it so we move on without acknowledging the experience.
- Medical units tend to be very busy with many different types of patients. Clinicians often come in and take care of tasks and equipment and don't demonstrate they are attending listening to the person.

What can be done in general to improve the listening skills of caregivers?

- ☑ Acknowledge patient concerns as valid, providing solutions when possible.
- ☑ Consider using simulation training to teach caregivers how to notice and respond to symptoms that they can't fix but can acknowledge. Acknowledging personal concerns validates emotional concerns inherent in the disease process. Simulation training can be effective at conveying the importance of body language to display compassion and understanding.
- ☑ Institute a 'Moment of Caring' to allow nurses to sit down with each patient for five minutes per day to have a one on one conversation. This builds relationships and establishes trust.

Empathy

Why would CHF patients be less likely to feel that staff did all they could to help with their pain?

- We need to address discomfort, not just pain. This may be more difficult because staff can tend to focus primarily on pharmacological approaches. Other, non-pharmacological methods might be more important when we are talking about discomfort in the CHF population.
- Physician and nurse communication tends to be more cognitive in nature—we tell the patient what we are going to do or what he can expect to have done to him. Our explanations tend to appeal to the mind rather than the emotions or sensory experience.

What could improve CHF patients' experience of empathy?

- ☑ Regardless of how many admissions the patient has experienced for CHF, to reduce anxiety be very clear about what is going to happen.
- ☑ Make it clear if something will be uncomfortable. This prepares the patient and creates opportunity to demonstrate empathy and concern for their discomfort.
- ☑ Don't just tell patients what is being done, tell them how it will make them feel. This provides additional information to reduce anxiety and also demonstrates perspective taking and understanding of their experience.

OPERATIONAL EFFICIENCY

Environment

Why might the experience of noise be more of a problem for CHF patients?

- CHF patients may lose sleep due to shortness of breath and nocturia. Nighttime wakefulness means more exposure to ambient noise which in turn prevents a return to sleep.

How can we improve the sleep experience of CHF patients?

- ☑ Address the symptoms that may prevent sleep for CHF patients.
- ☑ Remind staff of general practices to reduce noise so that all patients have a more restful experience.
- ☑ Close patients' doors at night.
- ☑ Dim hallway lights.
- ☑ Reduce the volume for monitors/phones.
- ☑ Provide earplugs/headphones for televisions.
- ☑ Change the schedule of routine tests when appropriate to avoid waking patients at night.
- ☑ Institute quiet hours between 9 pm and 6 am.

Conclusion

In order to prepare patients for effective disease management caregivers must first recognize and respond to the key physical and emotional struggles brought on by a CHF diagnosis, namely altered lifestyles, lengthy hospitalizations, diminished activity tolerance, edema, frequent urination, sleep deprivation, and poly-pharmacy. The focus on pain assessment may need to be adapted for the CHF population to ensure their unique concerns for comfort are addressed. It is equally as important to avoid assuming too much knowledge onto a patient simply because the condition is chronic. CHF is progressive therefore the patient's educational needs are ongoing and ever changing. Long term planning, individualized support and repetitive education are critical activities for advancing the patients' ability to manage this condition at home.

Thank you to the Subject Matter Expert work group participants for their contributions to this body of work. Please see Appendix A for a list of the organizations and individuals who contributed to this project.

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Appendix A: Subject Matter Experts

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