Patient-Identified Factors Related to Heart Failure Readmissions

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Background—Although readmission after hospitalization for heart failure has received increasing attention, little is known about its root causes. Prior investigations have relied on administrative databases, chart review, and single-question surveys.

Methods and Results—We performed semistructured 30- to 60-minute interviews of patients (n=28) readmitted within 6 months of index heart failure admission. Established qualitative approaches were used to analyze and to interpret data. Interview findings were the primary focus of the study, but patient information and provider comments from chart data were also consulted. Patient median age was 61 years; 29% were nonwhite; 50% were married; 32% had preserved ejection fraction; and median time from discharge to readmission was 31 days. Reasons for readmission were multifactorial and not easily categorized into mutually exclusive reasons. Five themes emerged as reasons cited for hospital readmission: distressing symptoms, unavoidable progression of illness, influence of psychosocial factors, good but imperfect self-care adherence, and health system failures.

Conclusions—Our study provides the first systematic qualitative assessment of patient perspectives concerning heart failure readmission. Contrary to prior literature and distinct from what we found documented in the medical record, patient experiences were highly heterogeneous, not easily categorized as preventable or not preventable, and not easily attributed to a single cause. These findings suggest that future interventions designed to reduce heart failure readmissions should be multifaceted, should be systemic in nature, and should integrate patient input.

Key Words: heart failure ■ patient-centered care ■ patient readmission ■ qualitative research ■ systems of care

Heart failure (HF) is the leading cause of hospitalization and readmission among older adults. Readmission rates among Medicare beneficiaries hospitalized for HF are ≈20% to 25% at 30 days and ≈50% at 6 months. At the institutional level, there is a >2-fold variation in risk-standardized readmission rates for HF patients who are hospitalized, and data from chart reviews suggest that many readmissions are thought to be preventable. Therefore, reduction in hospital readmissions has been identified as one of the pillars of Medicare reform, with public reporting and value-based purchasing now including measures of 30-day risk-adjusted all-cause readmission after hospital discharge for HF. Despite this recent attention to HF readmission, we know relatively little about its actual causes. Many existing studies that have explored factors associated with readmission have relied on secondary data sources such as randomized trial databases, registries, and Medicare administrative claims that were not designed specifically for this purpose. Those relatively few studies that delve deeper into reasons for HF readmission have relied on clinicians’ impressions gleaned through retrospective chart review data. Despite the fact that patients are in many ways best positioned to identify the underlying factors that contribute to their readmissions, relatively few studies have incorporated the patient’s perspective. The absence of patient experience and insights in past research may have contributed to our failure to develop widely effective and efficient interventions to reduce unnecessary readmissions. More than 2 years after the introduction of nationwide public reporting, these outcome measures have not budged significantly.

This research comes at an important time when a shift toward a patient-centered approach is being recognized as an essential aspect in creating change in the healthcare system and related policy. The purpose of our study was to systematically investigate patient perspectives about the reasons for their readmission after a hospital discharge for HF. We conducted a qualitative study using in-depth semistructured patient interviews to gather detailed information about the
WHAT IS KNOWN

• Heart failure is the leading cause of hospitalization and readmission among older adults and is high in the general population.
• Studies based on administrative databases, chart review, and single-question surveys speculate some reasons for heart failure readmission but fail to uncover root causes.

WHAT THE STUDY ADDS

• Insights into patient experiences reveal complex, multiple factors behind reasons for readmission.
• Reasons cited for hospital readmission include distressing symptoms, unavoidable progression of illness, influence of psychosocial factors, good but imperfect self-care adherence, and health system failures.
• Interventions to address heart failure readmissions should be multifaceted, should be systemic in nature, and should integrate patient input.

Patient-identified factors related to readmission and paired these findings with a detailed chart review to gain a provider perspective and to confirm circumstances surrounding hospitalizations.

Methods

Patients

Patients were recruited from an academic referral hospital and a community-based hospital. Patients discharged with a primary discharge diagnosis for HF who were then readmitted for any cause in the subsequent 180 days were eligible for the study. Exclusion criteria included <18 years of age, cognitive impairment, lack of legal capacity to consent, readmittance for a planned procedure (eg, elective implantable cardioverter-defibrillator placement), hospital discharge before the interview could be conducted, non-English speaking, or deemed inappropriate by hospital physician of record. Admissions to the academic referral hospital inpatient cardiology services were manually reviewed on weekdays from February 28 to May 13, 2011, for evidence in the electronic health record of hospitalization in the past 180 days (by International Classification of Diseases, Ninth Revision codes) from June 4, 2010, until March 25, 2011, followed by manual review of the electronic health record for confirmation of index hospitalization HF discharge diagnosis and other eligibility criteria. All admissions to the community-based hospital were electronically cross-matched against the integrated healthcare system HF database for HF hospitalization in the past 180 days (by International Classification of Diseases, Ninth Revision codes) from June 4, 2010, until March 25, 2011, followed by manual review of the electronic health record for confirmation of index hospitalization HF discharge diagnosis and other eligibility criteria. Of note, because of technical issues with the screening process that required reprogramming of the electronic match process as well as initial understaffing, the majority of patients at the community hospital were recruited in the later months of screening. The attending physician of record was approached before the patient was contacted. Eligible patients were approached, consented, and were interviewed within the next 24 hours while they were still in hospital. All patients recruited at the academic hospital agreed to participate; 2 patients recruited at the community hospital declined to participate. This study was reviewed and approved by the Kaiser Permanente Institutional Review Board, the Exempla Saint Joseph Hospital Institutional Review Board, and the Colorado Multiple Institutional Review Board.

Data Collection

Interviews

Because of the paucity of patient-centered assessments of HF readmission in the existing published literature, we chose a qualitative approach to identify themes that could be further explored in future quantitative research. In-depth semistructured open-ended interviews were conducted in the patient’s hospital room by a member of the research team (J.H.R., A.H., L.W., L.A.A.) using an interview guide (Appendix A in the online-only Data Supplement) containing 23 open-ended questions and follow-up probes to elicit further clarification. The interview guide was designed to explore inpatient experience during the index hospitalization and discharge transition, medical follow-up and care-seeking behavior between hospitalizations, experience during the readmission, adherence (diet, fluid, medications, and appointments), psychosocial issues, support in the postdischarge environment, physical activity, and perceived causes and precipitants of readmission. Interviews typically lasted between 30 and 60 minutes. Patients received a $25 gift card for participation. Four patients requested that their caregiver be present at the interview.

Chart Review

A detailed chart review was also conducted for each patient in the study to compare with the information from the interviews and to gather demographic, diagnostic, and postdischarge activities. The medical record was viewed (L.A.A.) from the date of the index HF admission through the discharge date of the readmission. Data collected through the chart abstraction were entered into a spreadsheet and included demographics, past medical history, cause of HF, left ventricular ejection fraction, home medications, inpatient therapies and procedures, and outpatient and emergency visits between the hospitalizations. Also included were any clinicians’ remarks about reasons for readmission.

Analysis of Interviews

Interviews were deidentified and transcribed by a member of the research team (J.B.) using a combination of direct quotes, paraphrasing, and summarization. They were then organized and coded in qualitative software (ATLAS.ti version 5.5, Scientific Software Development GmbH, Berlin, Germany). Analysis of patient interviews used largely a deductive approach because the semistructured interviews were designed to explore issues found in previous research to be related to HF readmission. We also used inductive methods to identify additional themes that emerged during the interviews. Two primary members of the research team (J.H.R., J.B.) performed the first- and second-level coding. Intermittent meetings were held with the other members of the team to confer about the codes, quotes, and interpretation of quotes and to decide when saturation of key findings had been reached.

Analysis of Chart Review and Comparison With Interviews

Chart information was reviewed and discussed by the team to describe the sample and to identify information that could be compared with the findings from the patient interviews. Patient and clinician data were compared side by side to identify any cases that reflected congruence or incongruence, conflicts, or discrepancies between accounts about the reasons for patient readmission. Chart documentation was also compared for self-care–related issues and social factors with patient interviews.

Results

Participants

We recruited 28 patients, 8 from the community-based hospital and 20 from the academic referral hospital. Overall, patients were representative of a broad range of the HF population, as summarized in Table 1. Compared with the community-based hospital, patients from the academic center were younger, had lower mean left ventricular ejection fraction, and included 2
Table 1. Patient Characteristics at the Time of Interview During Readmission

<table>
<thead>
<tr>
<th>Patient Characteristics</th>
<th>Academic Hospital (n=20)</th>
<th>Community Hospital (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, y</td>
<td>60 (29–88)</td>
<td>76.5 (68–88)</td>
</tr>
<tr>
<td>Female, n (%)</td>
<td>7 (35)</td>
<td>3 (38)</td>
</tr>
<tr>
<td>Race/ethnicity, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White, non-Hispanic</td>
<td>15 (75)</td>
<td>6 (75)</td>
</tr>
<tr>
<td>Black</td>
<td>2 (10)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>American Indian</td>
<td>1 (5)</td>
<td>1 (13)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (10)</td>
<td>1 (13)</td>
</tr>
<tr>
<td>Health insurance, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare</td>
<td>11 (55)</td>
<td>8 (100)</td>
</tr>
<tr>
<td>Private</td>
<td>7 (35)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Medicaid</td>
<td>2 (10)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Living at home independently, n (%)</td>
<td>19 (95)</td>
<td>8 (100)</td>
</tr>
<tr>
<td>Married, n (%)</td>
<td>11 (55)</td>
<td>3 (38)</td>
</tr>
<tr>
<td>Cardiac disease, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Documented coronary artery disease</td>
<td>8 (40)</td>
<td>5 (63)</td>
</tr>
<tr>
<td>History of atrial fibrillation</td>
<td>9 (45)</td>
<td>5 (63)</td>
</tr>
<tr>
<td>Left ventricular ejection fraction</td>
<td>0.30 (0.9–0.60)</td>
<td>0.55 (0.30–0.65)</td>
</tr>
<tr>
<td>Other medical history</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prior cerebrovascular accident, n (%)</td>
<td>1 (5)</td>
<td>1 (13)</td>
</tr>
<tr>
<td>Diabetes mellitus, n (%)</td>
<td>8 (40)</td>
<td>5 (63)</td>
</tr>
<tr>
<td>Chronic kidney disease, n (%)</td>
<td>10 (50)</td>
<td>2 (25)</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease, n (%)</td>
<td>5 (25)</td>
<td>4 (50)</td>
</tr>
<tr>
<td>Active smoking, n (%)</td>
<td>3 (15)</td>
<td>2 (25)</td>
</tr>
<tr>
<td>Recorded history of alcohol dependence, n (%)</td>
<td>2 (10)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Recorded history of depression</td>
<td>4 (20)</td>
<td>2 (25)</td>
</tr>
<tr>
<td>Index hospitalization, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systolic blood pressure, at admission, mm Hg</td>
<td>108 (86–160)</td>
<td>120 (100–138)</td>
</tr>
<tr>
<td>Creatinine, serum, closest to discharge, mg/dL</td>
<td>1.4 (0.6–3.2)</td>
<td>1.1 (0.8–3.8)</td>
</tr>
<tr>
<td>BNP, serum, closest to discharge, pg/mL</td>
<td>1165 (140–2089)</td>
<td>615 (249–1548)</td>
</tr>
<tr>
<td>Length of stay, d</td>
<td>4 (1–16)</td>
<td>3 (1–11)</td>
</tr>
<tr>
<td>Medications at discharge, n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loop diuretic</td>
<td>20 (100)</td>
<td>8 (100)</td>
</tr>
<tr>
<td>Loop diuretic dose 24 h, mg/24 h</td>
<td>100 (10-480)</td>
<td>80 (20-240)</td>
</tr>
<tr>
<td>β-Blocker</td>
<td>14 (70)</td>
<td>6 (75)</td>
</tr>
<tr>
<td>ACEI or ARB</td>
<td>10 (50)</td>
<td>5 (63)</td>
</tr>
<tr>
<td>Warfarin</td>
<td>12 (60)</td>
<td>4 (50)</td>
</tr>
<tr>
<td>Intervening ambulatory visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patients who had an ambulatory visit, n (%)</td>
<td>16 (80)</td>
<td>4 (50)</td>
</tr>
<tr>
<td>Time from discharge to visit, among those with a visit, d</td>
<td>5 (2–22)</td>
<td>5 (1–13)</td>
</tr>
<tr>
<td>Time from discharge to readmission, d</td>
<td>32 (3–126)</td>
<td>33 (6–166)</td>
</tr>
<tr>
<td>Readmission, length of stay, d</td>
<td>9 (2–67)</td>
<td>5 (2–6)</td>
</tr>
</tbody>
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ACEI indicates angiotensin-converting enzyme inhibitor; ARB, angiotensin receptor blocker; and BNP, brain natriuretic peptide. Values are median (range) when appropriate.

Reasons for Readmission

Based on patient experiences reported in the interviews, reasons for readmission coalesced into 5 main themes: distressing symptoms, unavoidable progression of illness, psychosocial factors, adherence with self-care recommendations, and health system failures. Thirteen patients stated the index admission was different from the current readmission; 10 patients stated they were admitted for the same reason. Eight patients indicated that the readmission was preventable; 6 felt that it was unavoidable; and 14 were not sure or did not give a direct response to the question. Although not all patients were able to give definitive answers on the preventability of their readmission, all patients pointed to 1 of the 5 main themes when discussing ways to prevent readmission. In a comparison of reasons for readmission, there were no remarkable differences between those admitted ≤30 days from their last admission and those admitted >30 days. The following sections describe our results in detail; accompanying quotes can be found in Table 2.

Distressing Symptoms

Most patients were initially focused on their physical symptoms (eg, discomfort from recurrent edema or shortness of breath). A minority of patients identified a specific diagnosis (eg, infection, blood loss) as the cause of readmission. Symptoms reported were clearly bothersome and often dominated the patient-reported experience leading up to readmission (Table 2, quote 1).

Unavoidable Progression of Chronic Disease

Progression of HF was identified by many patients as a primary reason for readmission. Attribution of readmission to an inexorable worsening of HF was often discussed at the end of the interviews, sometimes discussed in terms of end-of-life care, fears about dying, decreased efficacy of medications, or involvement of other body systems (quote 2). Even if the readmission was primarily because of worsening HF symptoms, almost half the patients cited chronic comorbidities as relating directly or indirectly to their readmission. Pulmonary disease was most commonly implicated (eg, chronic obstructed pulmonary disease exacerbation, asthma), with diabetes mellitus and renal disease also mentioned multiple times (quote 3).

Influence of Psychological and Social Environment Factors

The psychosocial context for each patient was often cited as having a role in readmission. Many patients reported having adequate support from family, friends or a caregiver; however, for some, adequate support or resources were not always available when needed (eg, transportation to medical
appointments, lack of meals meeting diet restrictions). Economic (quotes 4 and 5) and psychosocial (quote 6) issues were most prevalent as contributors to readmission in our study. Fifteen patients indicated financial stress; 6 admitted that this occasionally prevented them from purchasing medications/obtaining needed care, whereas 9 patients indicated that, because of either good medical insurance or neglecting other bills to afford care and medications, they still obtained needed care. The ability to cope with HF was a challenge for some patients because of previous psychological issues and usually brought on by the illness itself. Distressing anxiety and depression were reported by 10 patients.

**Self-care and Adherence With Medical Recommendations**

Self-care issues—specifically diet, fluid restrictions, weight checking, medication adherence, and exercise—were common but rarely cited as the overarching reason for readmission. Nine patients reported they were compliant in all self-care categories; all patients stated they were compliant in at least 1 area; and many admitted episodes of nonadherence constituting fairly minimal infractions. Of those who described noncompliance, the most common infraction related to diet (quotes 7 and 8). For those who were noncompliant with salt restrictions, lack of control over their food preparation was often cited such as food preparation by their home-delivered meal service, family members, or a nursing facility and an inability to afford healthy food (food stamps). In general, eating outside the home was cited as the primary reason for noncompliance, the most common infraction related to diet (quotes 7 and 8). For those who were noncompliant with salt restrictions, lack of control over their food preparation was often cited such as food preparation by their home-delivered meal service, family members, or a nursing facility and an inability to afford healthy food (food stamps). In general, eating outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance, the most common infraction related to diet (quotes 7 and 8). For those who were noncompliant with salt restrictions, lack of control over their food preparation was often cited such as food preparation by their home-delivered meal service, family members, or a nursing facility and an inability to afford healthy food (food stamps). In general, eating outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence ining outside the home was cited as the primary reason for noncompliance. Patients reported a high rate of adherence

### Table 2. Pertinent Quotes for Each Theme

<table>
<thead>
<tr>
<th>Distressing symptoms</th>
<th>1. Patient: “Shortness of breath and chest pain, flown here a few days ago, … I just couldn’t get any air, so I went to local hospital to try to figure out if I just needed some oxygen or if something else was going on.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unavoidable progression of chronic disease</td>
<td>2. Patient: “I am at the later stages of it now. They say my heart is getting real stiff.”</td>
</tr>
<tr>
<td></td>
<td>3. Patient: “Diabetes has a deteriorating effect on your life. If you have high blood pressure, that has to be controlled. So they all have an impact on weight. Weight gain puts pressure on your heart … it’s all integrated and interconnected and one has an effect on another down the stretch.”</td>
</tr>
<tr>
<td>Influence of psychological and social environment factors</td>
<td>4. Patient: “I have a problem getting to the pharmacy, and paying … am not working, without money, you can’t buy medication.”</td>
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<tr>
<td></td>
<td>5. Caregiver; “It’s impossible to eat a good, proper, nice balanced diet when you are trying to scrape and save every penny on food stamps. You don’t have the luxury to be able to buy fresh vegetables.”</td>
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<tr>
<td></td>
<td>6. Patient: “When I think about it, it is when I’m depressed that I eat stuff I shouldn’t and drink too much. … I just want to feel better, I just want to get to some kind of normal life.”</td>
</tr>
<tr>
<td>Self-care and adherence with medical recommendations</td>
<td>7. Patient: “Yeah, I was meeting goals for most part, but did go over a few times. I’m not going to lie.”</td>
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<tr>
<td></td>
<td>8. Patient: “I eat more salt in the hospital than I do at home! I follow the rules always when doctor tells me what to eat. Salt is not my problem. Diet is not my problem. It is hard to limit my salt intake but not as hard as it was.”</td>
</tr>
<tr>
<td>Health system factors</td>
<td>9. Caregiver; “Last time, he had been here 15 days and they just wanted to get us out. But he had already started to gain, 2lbs, before he even left. But it never stopped; it just kept going up and up and up.”</td>
</tr>
<tr>
<td></td>
<td>10. Patient: “When I left I thought I was ok, but doc said that in retrospect she should have kept me a few more days.”</td>
</tr>
<tr>
<td></td>
<td>11. Patient: “I wasn’t ready, but there wasn’t much they could do.”</td>
</tr>
<tr>
<td></td>
<td>12. Patient: “I had a primary care physician there and it was really easy to get back and forth from his office. So I went there and they had no idea what to do with me.”</td>
</tr>
<tr>
<td></td>
<td>13. Patient: “Patients are humans. Doctors forget, … they are so into their routines and dealing with [sick] people every day, and splitting out orders …”</td>
</tr>
<tr>
<td></td>
<td>14. Patient: “Biggest problem, our doc at home, he is a great communicator and talks to people up here before he does anything, but his lack of knowledge of heart disease, he doesn’t do something or doesn’t do something enough.”</td>
</tr>
</tbody>
</table>
One patient noted that the readmission could have been prevented if it had not been for provider-related issues that prevented the patient from seeing a doctor during the 4 days after discharge. Formal support in the form of home care, hospice, or palliative care was rarely mentioned by patients as part of their treatment follow-up.

Broader health system issues were also identified by patients. Some were general (eg, need of better care coordination or better communication between doctors and patients) whereas others were specific (eg, need for assistance with menu planning, better communication about test results, or better use of resources, citing inefficiencies of the emergency department). A few patients were clearly frustrated with attitudes and insensitivity of providers generally (quote 13), and some wished to better convey the experience of living with HF to their healthcare providers. Several patients recommended that their providers be more efficient and knowledgeable at managing unique HF issues (quote 14).

**Patient and Provider Comparison on Reasons for Readmission**

Thirteen of the patient interviews and medical record data had congruent reasons for patient readmission; 12 cases had too little information or included information that was not comparable; and only 3 cases had conflicting accounts. Among the 9 patients who felt that they had left the hospital too early, we found that only 1 provider noted that it was possible that the patient may have been discharged prematurely (although this is not a routine assessment completed by providers). Few charts showed evidence that the physician of record inquired in depth into patients’ social support systems and postdischarge environment. A couple of patients who reported excellent adherence behavior also expressed that their clinicians did not trust the patients’ reported behavior.

**Discussion**

Systematic assessment of patient experiences and opinions about recent HF hospital readmission provided a distinctly different impression of the HF readmission problem than what is generally conveyed in most published literature, existing policy statements, and the many interventions to reduce readmissions. Taking time to listen to patients in an open-ended but systematic manner (rather than through directed single-question items and surveys) captured a greater degree of nuance and complexity surrounding readmission. The most important findings from this analysis are that patient experiences and perspectives are multifaceted, HF readmissions can rarely be attributed to single preventable events, and an overattribution of the current HF readmission discussion to self-care deficiencies may distract both patients and providers from working to understand the true root causes at play.

**Heterogeneity and Complexity, Not Isolated Preventable Causes**

For quality measures and intervention design purposes, much effort has been put into categorizing readmissions as either preventable or unpreventable. Analysis of interviews showed that responsibility for readmission can reside with the patient, individual providers, or the healthcare system or simply may be a consequence of disease progression. Interviewed patients usually implicated a combination of several or all of these at some point. Thus, the common practice of categorizing readmissions as preventable or nonpreventable is largely artificial. Additionally, we found a particular paucity of descriptions in the medical records of the postdischarge environment.

Healthcare delivery systems have many temporally affected and interdependent components that make quality improvement challenging. Therefore, we recommend a reframing of the readmission discussion to one that better recognizes the heterogeneity, complexity, and interrelatedness of a multitude of factors that lead to readmission. The implication is that alternative types of data (eg, longitudinal, patient and provider perspectives, multilevel) are likely needed to truly understand the complex nature of readmission causes and to inform interventions to prevent them. Although this study involved a relatively small sample size, we believe that more patient interviews and greater population heterogeneity are only likely to accentuate this principal finding.

**Self-care Shades of Gray**

Although our interviews support a role for self-care and medical adherence in HF readmissions, the more dominant finding was that the issue of self-care seemed to be overemphasized within the readmission discussion. Reported adherence to diet, fluid restrictions, exercise recommendations, medications, and medical appointments was not perfect, but on the basis of our interpretation of interview responses, patient adherence was perceived overall as good by our team. Other qualitative work investigating patients living with HF have shown that adherence to the medical regimen is hard work and that physicians and patients had divergent understandings of that work. Other objective studies of adherence have frequently documented significant nonadherence. This has important implications for how much we pay attention to the self-care problem because it contributes to readmission rates.

In our study, some patients clearly felt mistrust or perceived a lack of understanding from the medical community when it came to self-care. Literature suggests that a trusting patient–provider relationship is a key component to adherence and that mistrust or potentially adversarial dynamics could be counterproductive. This implies that education needs to go beyond merely telling patients what to do: adherence and self-care education must be more comprehensive to deal with factors that underlie nonadherence. Ultimately, our patients’ insights suggest that readmission initiatives should reframe the discussion from an all-or-none view of adherence to a more nuanced approach reflective of the real world. We recommend that future research into postdischarge adherence shift from individual blame toward an empowerment and systems approach that considers the big picture.

**Patient Recommendations for Health System Changes**

Nearly all patients, regardless of reasons for readmission, highlighted failures of the healthcare system to adequately meet their perceived needs. Some patients said they did not
feel ready to be discharged. Most patients reported (and chart reviews confirmed) that they had follow-up visits scheduled after hospital discharge but acute medical issues often arose before the follow-up happened. Only a few of the patients in our sample were currently enrolled in some kind of home health services despite relatively advanced disease. Several patients reported that their local physicians did not have adequate expertise to manage their HF and others communicated that the communication between the acute care and outpatient care providers was lacking; some patients stated both. Taken together, these insights lead us to believe that successful transitional care policies are likely to promote multimodal interventions that start early in the hospitalization, include contact within 48 to 72 hours after discharge, facilitate communication between various healthcare providers, and address broad patient concerns (ie, medical, social, economic) in the postdischarge environment.25,26

Overall, the team found it surprisingly difficult to compare patient perspectives derived from interviews with provider perspectives derived from chart review, questioning the comprehensiveness and value of chart review in isolation. This appeared to be largely attributable to the minimal amount of information that providers document on the patient-oriented topics we explored. Unfortunately, within the current structure of inpatient health care, providers are not necessarily incentivized to focus on these issues. If policy and reimbursement changes continue to focus attention on transitions of care and readmissions, we would expect the medical record to better reflect clinician focus on causes of readmission and the postdischarge environment and to increase the role of case management/social work.

Limitations

A number of considerations are relevant to the interpretation of these findings. Although 2 hospital types were represented, the majority of the patients were recruited from an academic medical center with a referral-based HF/transplantation inpatient service. The result was that study patients were younger and with greater left ventricular systolic dysfunction than seen in the overall HF population. We also recruited patients from a single metropolitan area whose experiences may not necessarily generalize to other regions of the country. Because this study did not include detailed interviews with providers but instead relied on chart review to glean the provider perspective, our ability to accurately assess congruence in patient versus provider perspective is limited. The small sample size of this exploratory qualitative study may limit the ability to generalize our results. Despite these potential concerns, study patients represented a broad spectrum of race, ethnicity, sex, and living situations (Table 1) covered by a wide range of health insurance types and cared for in 2 completely different health delivery systems. Additionally, analysis showed thematic saturation indicating that more interviews were considered unlikely to significantly enhance the findings presented here. The investigators were well versed in existing literature on HF readmission and therefore did not come to the conduct and analysis of patient interviews without some preconceived notions about factors related to HF readmissions. Although this may have partially influenced questioning and interpretation, such preexisting knowledge is inherent to most qualitative analyses and can serve to direct the study to those areas in greatest need of clarification and new insights.

Conclusion

Our study provides the first systematic qualitative assessment of patient perspectives on HF readmission. This research also addresses gaps in needed patient-centered research conducted for the improvement of health systems. Contrary to much of the published literature and distinct from chart documentation, we found that patient perceptions of factors leading to HF readmission are heterogeneous, multifaceted, and not easily categorized as preventable or not. These findings suggest that policies and interventions aimed at reducing unnecessary HF readmissions should better integrate patient input. Successful interventions are likely to be multifaceted and directly responsive to a range of patient needs.

Acknowledgments

We would sincerely like to thank the following individuals: Ann Wells, MD; Jeanine M. Compesi, DO; Shelley Cooper, PMP, MBA; and the entire Kaiser Permanente Colorado Heart Failure Governance Group for their participation. We also would like to sincerely thank the University of Colorado Division of Cardiology staff for assistance with screening, Josh Gordon for recruiting and consenting patients, and Lisa Pieper and Gwendolyn Wade for their assistance with patient protection and privacy issues.

Sources of Funding

This study was supported by the National Institutes of Health (NIH) National Center for Advancing Translational Sciences, Colorado Clinical and Translational Sciences Institute grant UL1 TR000154. The contents are the authors’ sole responsibility and do not necessarily represent official NIH views.

Disclosures

Dr Allen has received consulting fees from Amgen, Johnson & Johnson, and the Robert Wood Johnson Foundation, and is currently supported by grant 1K23HL105896 from the National Heart, Lung and Blood Institute. The other authors report no conflicts.

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Circ Cardiovasc Qual Outcomes. published online February 5, 2013;
Circulation: Cardiovascular Quality and Outcomes is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
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Print ISSN: 1941-7705. Online ISSN: 1941-7713

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://circoutcomes.ahajournals.org/content/early/2013/02/05/CIRCOUTCOMES.112.967356

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Appendix A
Interview Questions

1.) Tell me about what reason or reasons you may have needed to be readmitted to the hospital this time?
2.) Tell me about anything that you think contributed to your having to come back to the hospital? (probe here about whether or not heart failure was the main reason why they were admitted)
3.) Please tell me more about what you are being treated for while you are here.
4.) Do you think your most recent hospital admission could have been prevented?
   i. (If it was preventable), what could have been done differently?
   ii. (If it was going to happen no matter what, probe about whether could it have been delayed. If so probe about how.)

Now let’s shift to what you remember about your LAST hospitalization (perhaps remind them of the date).

5.) Tell me in your own words why you were in the hospital?
6.) Do you believe those reasons for the last hospitalization to be similar or different than the reasons you mentioned before about this time in the hospital? How so?
7.) What kind of things did your doctors do for you during that hospitalization (again maybe use date so they are reminded you are talking about before)?
8.) Were you ready to go home when you left the hospital after your last admission?
   i. Where did you go when you left the hospital? (e.g. back to home)
9.) In hindsight, tell me anything about that hospital visit that you would have liked to have happened differently?
   i. Was there something you know now that you wished you knew then?
   ii. What would you do differently this time when you leave the hospital?
10.) Tell me about what things were like for you during the time from your last hospitalization to this current one.
11.) Describe what follow up or appointments and help were arranged for you after your last hospital visit. How long was it from when you left the hospital until you were asked to come and see someone?
12.) How long between when you started feeling worse and when you contacted your health care provider or asked for medical help? (ask if they regret not calling sooner)
13.) Tell me about how your medications are managed.
   i. How do you keep track of the medications you need to take each day?
   ii. Do you use a pill-box? Do you ever forget if you took your medications?
   iii. Do you manage your own or does someone else help you?
   iv. Do you ever get confused about your medications? How so? Why?
   v. Do you ever miss or skip your medications? Now? In the past? If so why?
   vi. What happens when you run out of your medications? (then they can say “I never do” if that is the case.)
   vii. Do your medicines make you feel better or worse?

SOCIAL SUPPORT
14.) Let’s talk a little more about what it’s like for you at home. Where is home for you? Is that where you were before you were admitted this time? (if not, probe about that place)
15.) Whom do you live with? Do you have help? From whom?

DIET
16.) Tell me about your diet and how you see it related to your health. (probe about whether they think their diet relates to the most recent hospitalization first, then about others)
17.) Do you follow any salt/sodium restriction?
18.) What has your healthcare provider told you about your diet?
19.) Do you feel like you know how much sodium is in your food?
20.) How hard is it to limit salt intake?
**FLUID STATUS / MONITORING**

21.) Was fluid (swelling, bloating, dehydration) related to your need to come back to the hospital? How so? Was your weight increasing?

**ALCOHOL, TOBACCO, DRUGS**

22.) Do you use tobacco, alcohol, or recreational drugs? Describe how these things relate to your health (probe if they view it as a cause of rehospitalization).

**NSAIDS**

23.) Do you know what an NSAID is? (If no, define and list medications. If yes, then continue)

24.) Have you taken any NSAID medications recently, such as ibuprofen (Advil, Motrin), naproxen (Aleve, Naprosyn), diclofenac (Voltaren).

a. If so, when and how much? Have you been told to or not to take these medications?

b. Why do you need to take them?

**ACTIVITY**

25.) Tell me how your daily activities relate to your heart failure (probe about whether or not they think these activities contributed to the readmission).

**PSYCHIATRIC, EMOTIONAL, SOCIAL ECONOMIC**

26.) What physical symptoms did you have before coming back to the hospital? (e.g. chest pain, palpitations / arrhythmia, syncope, cough, bleeding, fever...)

27.) Tell me about any emotional issues going on that may have affected your health in general or need to come back to the hospital? (e.g. depression)

28.) Describe how financial issues affect your ability to deal with your heart failure and may have affected your need to come back to the hospital?