

# Understanding patient-centred readmission factors: a multi-site, mixed-methods study

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## ABSTRACT

**Importance** Patient concerns at or before discharge inform many transitional care interventions; few studies examine patients' perceptions of self-care and other factors related to readmission.

**Objectives** To characterise patient-reported or caregiver-reported factors contributing to readmission.

**Design, setting and participants** Cross-sectional, national study of general medicine patients readmitted within 30 days at 12 US hospitals. Interviews included multiple-choice survey and open-ended survey questions of patients or their caregivers.

**Measurements** Multiple-choice survey quantified post-discharge difficulty in seven domains of self-care: medication use, contacting providers, transportation, basic needs (eg, food and shelter), diet, social support and substance abuse. Open-ended responses were coded into themes that added depth to the domains above or captured additional patient-centred concerns.

**Results** We interviewed 1066 readmitted patients. 91% reported understanding their discharge plan; however, only 37% reported that providers asked about barriers to carrying out the plan. 52% reported experiencing difficulty in  $\geq 1$  self-care domains ranging in frequency from 22% (diet) to 7% (substance use); 26% experienced difficulty in two or more domains. Among 508 patients (48% overall) who reported no difficulties in these domains, two-thirds either could not attribute their readmission to any specific difficulty (34%) or attributed their readmission to progression or persistence of their disease despite following their discharge plan (31%). Only 20% attributed their readmission to early discharge (8%), poor-quality hospital care (6%) or issues such as inadequate discharge instructions or follow-up care (6%).

**Limitations** The study population included only patients readmitted at academic medical centres

and may not be representative of community-based care.

**Conclusion** Patients readmitted within 30 days reported understanding their discharge plans, but frequent difficulties in self-care and low anticipatory guidance for resolving these issues after discharge.

## INTRODUCTION

Unplanned hospital readmission affects 15%–30% of Medicare patients with costs exceeding \$17 billion annually.<sup>1</sup> In 2012, Medicare introduced a readmission penalty to reduce hospital readmission rates<sup>2</sup> and, in 2013 alone, 66% of eligible US hospitals were penalised, resulting in a total of \$227 million in withheld reimbursements.<sup>3</sup> Given this national focus, many interventions have been studied to reduce readmissions.<sup>4</sup> In light of mixed results from previous studies, the Patient-Centered Outcomes Research Institute (PCORI) recently awarded over \$50 million to evaluate new interventions to improve transition outcomes. Unfortunately, the precise targets for these interventions are still not clear as many studies using clinical or administrative data to identify risk factors to predict readmission have had limited success.<sup>5</sup>

More recent efforts to understand readmissions have shifted from a provider-centric or hospital-centric model to a patient-centric approach for understanding the experience and perspective of patients as they transition from hospital to home. Patients and their caregivers likely have an important perspective and even expertise as they encounter problems such as fragmentation, inadequate education or social barriers to care. Prior research has examined specific aspects of the hospital discharge process such as

patient understanding of discharge instructions, medications, follow-up appointments,<sup>6–9</sup> misaligned transition goals,<sup>10</sup> unmet needs<sup>11</sup> or perceptions about preventability.<sup>12</sup> Few studies, however, have focused on the experience of readmitted patients specifically to understand ‘what went wrong’ after discharge from the patient’s perspective.<sup>13–15</sup> Furthermore, these patient-centred studies were each single site and none have combined data both validated survey instruments and open-ended responses, thus limiting the depth and generalisability of findings.

To address this knowledge gap and to guide and prioritise readmission prevention strategies, we conducted a prospective, mixed-methods, multi-site study that enrolled patients and their caregivers at the time of readmission and used in-person interviews. Our objectives were to quantify the frequency of patient-reported and caregiver-reported post-discharge barriers to recovery and further characterise these barriers using their own words.

## METHODS

### Study setting, approach and participant selection

Our study took place at 12 academic medical centres in the Hospital Medicine Re-engineering Network (HOMERuN): University of California, San Francisco (Coordinating Center), California Pacific Medical Center, and San Francisco General Hospital (all three in San Francisco); Beth Israel Deaconess Medical Center, Brigham, and Womens’ Hospital (both in Boston, Massachusetts, USA); Christiana Care Health System (Wilmington, Delaware, USA); Northwestern Memorial Hospital and University of Chicago Hospital (both in Chicago, Illinois, USA); University of Michigan Hospital (Ann Arbor, Michigan, USA); Hospital of the University of Pennsylvania (Philadelphia, Pennsylvania, USA); University of Washington, Harborview Hospital (Seattle, Washington,

USA) and Vanderbilt University Hospital (Nashville, Tennessee, USA). HOMERuN is a collaborative created in 2011 that seeks to measure, benchmark and improve the efficiency, quality and outcome of care in the hospital and afterwards.<sup>16</sup> See [table 1](#), for a summary of hospital characteristics by site.

We chose a mixed-methods design to examine patient and caregiver perspectives on barriers to recovery leading to readmission because we wanted both to quantify the extent to which patients endorsed known risk factors for readmission (such as limited engagement in discharge planning or poor understanding of the post-discharge plan) and qualitatively explore patients’ perspectives on the inherent complexity of recovery after hospitalisation that is difficult to elicit with multiple-choice questions.<sup>17 18</sup> We focused on patients who had recently been readmitted as they have direct experience with the phenomenon of interest.<sup>19</sup>

We used a random-number generator to select participants from a daily list of all readmitted patients at each site. All patients were admitted and subsequently readmitted to the medical service of the same hospital within 30 days of initial hospital discharge between January 2012 and August 2013. We excluded patients who were aged <18, who were critically ill (intensive care unit admissions) or who did not speak English. We also excluded patients with cognitive impairment if they did not have a caregiver at bedside who agreed to speak on the patient’s behalf. All participants gave informed consent and the Institutional Review Boards of each hospital approved all research procedures. The Association of American Medical Colleges provided support (matching funds for each site) but had no direct role in the study.

### Survey instrument design and data collection

We collected quantitative data using a 22-item interview tool (see online supplementary appendix S1) which was

**Table 1** Hospitals participating in HOMERuN

| Hospital                                                                                      | Setting                | Size (beds) | Hospital-wide readmission rate (%) |
|-----------------------------------------------------------------------------------------------|------------------------|-------------|------------------------------------|
| University of California, San Francisco (Coordinating Center, San Francisco, California, USA) | Public, large city     | 559         | 16.3                               |
| Beth Israel Deaconess Medical Center (Boston, Massachusetts, USA)                             | Private, large city    | 649         | 17.0                               |
| Brigham and Womens’ Hospital (Boston, Massachusetts, USA)                                     | Private, large city    | 779         | 17.2                               |
| California Pacific Medical Center (Sutter Hospitals, San Francisco, California, USA)          | Private, large city    | 785         | 14.8                               |
| Christiana Care Health System (Wilmington, Delaware, USA)                                     | Private, small city    | 913         | 15.7                               |
| Northwestern Memorial Hospital (Chicago, Illinois, USA)                                       | Private, small city    | 894         | 18.0                               |
| San Francisco General Hospital (San Francisco, California, USA)                               | Safety-net, large city | 441         | 16.5                               |
| University of Chicago (Chicago, Illinois, USA)                                                | Private, large city    | 577         | 17.2                               |
| University of Michigan Hospital (Ann Arbor, Michigan, USA)                                    | Public, small city     | 899         | 17.5                               |
| University of Pennsylvania (Philadelphia, Pennsylvania, USA)                                  | Private, large city    | 784         | 18.3                               |
| University of Washington, Harborview Hospital (Seattle, Washington, USA)                      | Safety-net, large city | 413         | 15.5                               |
| Vanderbilt University (Nashville, Tennessee, USA)                                             | Private, small city    | 966         | 17.2                               |
| HOMERuN, Hospital Medicine Re-engineering Network.                                            |                        |             |                                    |

piloted with patients and modified with their input. Fifteen questions were drawn from previously validated instruments to measure patient understanding and engagement in care<sup>20</sup> and interpersonal processes of care.<sup>21</sup> To further assess patient-centred difficulties after discharge, we added seven questions to address specific self-care issues based on clinical consensus from co-investigators at all participating sites and a conceptual framework for an 'ideal' transition in care published previously by HOMERuN investigators.<sup>22</sup> These issues were: taking medications as directed, contacting providers, transportation, basic needs such as food and shelter, following recommended diet, maintaining adequate social support and avoiding drugs and alcohol. All questions in these domains used the same question stem ('After I left the hospital, I had difficulty with...') and used standardised, 5-point ordinal responses (Likert scale from strongly agree to strongly disagree and frequency scale from always to never). All questions and responses were read to patients by Research Assistants (RAs) in a structured interview format.

We also collected qualitative data from these structured interviews facilitated by a discussion guide with three open-ended questions about post-discharge readmission factors: 'Can you tell me about any problems you've had getting better...' and 'is there anything you think might have helped you stay out of the hospital this time...' and 'anything else you can tell me about returning home?' We created questions for the discussion guide based on clinical consensus and recent qualitative studies of transitions in care,<sup>6 7-10</sup> including one conducted by the first author (SRG) with in-depth interviews of patients discharged from one of our participating hospitals<sup>11</sup> (see online supplementary appendix S1). These open-ended questions were piloted with patients and modified based on their feedback, for example: we reframed the initial question from, 'Why do you think you were readmitted to the hospital?' to focus on problems encountered or things that could have helped avoid readmission as patients tended to view the readmission event as a medical decision (eg, physician-driven). Open-ended questions were asked after multiple-choice questions at the end of the structured interview to extend findings from closed-ended items and to provide an additional dimension of respondents' insights into their readmission.

RAs conducted all structured interviews at the patient's bedside. Each RA received study-specific training in interviewing techniques including how to use additional discussion probes based on survey responses as well as additional guidance as needed during weekly all-site conference calls. RAs read all structured interview questions aloud to patients or caregivers and manually transcribed their responses into a single, secure website (REDCap).<sup>23</sup> RAs read patient responses to open-ended questions back to the patient before finalising each entry to confirm accuracy.

### Data analysis

We used descriptive statistics to analyse quantitative responses to multiple-choice questions focused on the difficulties that patients encountered carrying out specific aspects of the plan of care in seven domains of self-care after discharge (medication use, contacting providers, transportation, basic needs such as food and shelter, diet, social support and substance abuse).

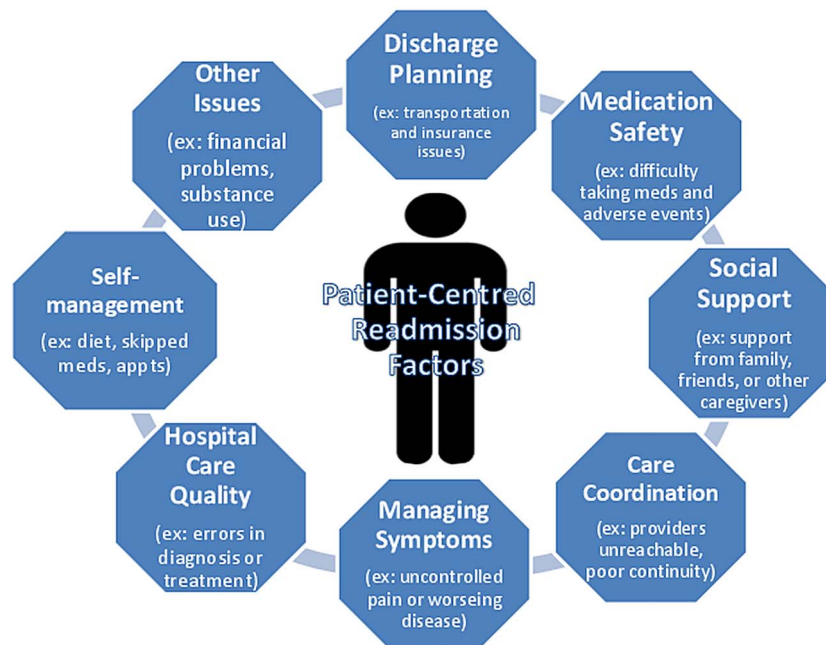
We qualitatively analysed all open-ended responses from our survey using a thematic analysis approach to iteratively develop and refine codes which identify important concepts that emerge from the data.<sup>13-15</sup> Two members of the research team (SRG, JDH) coded all of the transcripts and the entire team reviewed our code structure throughout the analytic process, revising the scope and content of codes as needed. Disagreements in coding were resolved through negotiated consensus. The final code structure contained 15 codes which we organised into eight overarching themes on patient-centred readmission factors (figure 1).

Finally, to better understand patient-centred readmission factors, we selected representative quotations from each qualitative theme to add depth and specific examples of how these factors affected patient attempts to recover after discharge. Given that 48% of respondents reported no difficulties in the seven multiple-choice questions on self-care domains listed above, we also calculated the percentage of these patients who provided open-ended responses in each of our 15 code categories to provide some estimate of proportionality. We did not attempt to quantify the open-ended responses of the 52% of respondents who had quantitative data from multiple-choice questions as their open-ended responses generally corresponded to the domains they selected in the seven multiple-choice questions.

### RESULTS

We analysed results from 1066 readmitted patients (table 2); 87% (928) were patient-only interviews, 6% (62) were caregiver-only interviews, 7% (73) were with patient and caregiver together interviews. Mean age was 56 years (range: 18-100), 62% (660 patients) were not married or cohabitating with a partner, 84% (890 patients) did not have an identified caregiver, 82% (870 patients) were discharged to home on the previous admission and 41% (439 patients) had one or more advanced comorbidity.

Table 2 also provides patient responses to structured questions about engagement. The vast majority of patients, 91% (970 patients), reported that they understood what they needed to do to take care of themselves at the time of discharge from their index admission. Patients also reported high levels of engagement in discharge planning: 73% (774 patients) reported they had time to say what they thought was important and 75% (797 patients) reported their



**Figure 1** Overarching themes on patient-centred readmission factors.

preferences were incorporated into the post-discharge plan of care. In contrast, only 37% (399 patients) reported that the hospital team asked if they might have problems actually carrying out specific aspects of this plan such as taking their medications correctly.

Table 3 presents patient responses to multiple-choice questions in seven domains of self-care: 52% (558 patients) experienced one or more of the following difficulties: (1) following diet as directed (22%); (2) transportation to follow-up care (20%); (3) taking medications as directed (18%); (4) social support (15%); (5) contacting providers when needed (14%); (6) basic needs such as food and shelter (11%) and (7) alcohol or drugs (7%). Among patients who reported any difficulty, approximately half reported only one difficulty (27% of the total sample) and half (26% of the total) reported two or more difficulties. Representative quotes from open-ended responses by the 558 patients (52%) who reported difficulties in the self-care domains above are also presented in table 2. Open-ended quotes by these patients focused on issues related to the seven domains of self-care stated above; we did not quantify the frequency of other issues present in some responses as these were rare and non-representative of the whole.

Table 4 presents responses to open-ended questions by 508 patients (48%) who reported no difficulties in seven domains of self-care (multiple-choice questions) stated above: most of these (337/508 or 65%) fell into two categories: 34% (171/508) reported they experienced no difficulties they could associate with their readmission (including ‘new’ or unrelated problems) or they did not understand what went wrong; 31% (156/508) reported that progression or

persistence of their disease or symptoms led to their readmission despite being able to carry out their discharge plan without difficulty. Additionally, a relatively small proportion (14%; 71/508) reported their readmission could have been avoided if their index admission had been longer (8%; 39/508) or of higher quality (6%; 32/508). Only 6% (31/508) reported problems with typical transition issues such as unclear discharge instructions or poor follow-up care. The remaining categories each contained 5% or less of responses. Most patients answered all three open-ended questions; only 24 patients (2%) declined to answer any of these questions.

## DISCUSSION

In this prospective study of 1066 patients readmitted at 12 hospitals across the US—the largest multi-site study of readmissions from the patient perspective to date—most patients reported they understood their post-discharge plan of care but were not asked about anticipated difficulties carrying out specific aspects of that plan. Despite high levels of perceived engagement in discharge planning and satisfaction with the discharge process, most patients encountered unanticipated problems after discharge that they were unable to solve; relatively few reported that their readmission was due to a new problem or occurred in spite of following their discharge plan without any problems they could discern.

Our findings built on recent patient-centred studies of readmission suggest that there are still important resource gaps in the post-acute phase which patients believe led to their readmission.<sup>6 7</sup> Indeed, results from our qualitative analyses of open-ended patient

**Table 2** Patient characteristics (n=1066)

| Demographics                                                                                                                          | Number (%)                       |
|---------------------------------------------------------------------------------------------------------------------------------------|----------------------------------|
| Mean age (range)                                                                                                                      | 56 (18–100)                      |
| Person interviewed                                                                                                                    |                                  |
| Patient                                                                                                                               | 928 (87)                         |
| Caregiver                                                                                                                             | 62 (6)                           |
| Both                                                                                                                                  | 73 (7)                           |
| Married or cohabitating with partner                                                                                                  | 406 (38)                         |
| Caregiver identified at time of readmission                                                                                           | 176 (16)                         |
| <i>Clinical characteristics</i>                                                                                                       |                                  |
| Comorbidities                                                                                                                         |                                  |
| CHF (stage III or stage IV)                                                                                                           | 64 (6)                           |
| COPD (O2-dependent or FEV <sub>1</sub> <1 L)                                                                                          | 76 (7)                           |
| Cancer (any)                                                                                                                          | 163 (15)                         |
| Stroke (ischaemic or haemorrhagic)                                                                                                    | 77 (7)                           |
| Dementia (Parkinson's or other neurodegenerative disorder)                                                                            | 26 (2)                           |
| ESRD (CKD IV, GFR<30 or haemodialysis)                                                                                                | 140 (13)                         |
| ≥1 above conditions                                                                                                                   | 439 (41)                         |
| Discharge location from index admission                                                                                               |                                  |
| Home                                                                                                                                  | 917 (86)                         |
| Homeless (shelter or streets)                                                                                                         | 56 (5)                           |
| Rehabilitation (subacute, acute or long-term acute care)                                                                              | 43 (4)                           |
| Nursing home                                                                                                                          | 24 (2)                           |
| Other (eg, hospice, psychiatric or other acute care hospital)                                                                         | 26 (2)                           |
| Post-discharge follow-up visit scheduled prior to readmission                                                                         | 735 (69)                         |
| Patient able to attend follow-up visit prior to readmission                                                                           | 384 (36)                         |
| Patient identifies having a primary care provider                                                                                     | 906 (85)                         |
| <i>Patient-reported engagement in discharge planning</i>                                                                              |                                  |
| 'When you were getting ready to leave the hospital, how often did you have enough time to say what you thought was important?'        | Always or often<br>774 (73)      |
| 'How often did you feel pressured by them to have a treatment you were not sure you wanted?'                                          | Never or rarely<br>(78)          |
| 'When you were getting ready to leave the hospital, did they ask if you might have problems actually following the recommended plan?' | Always or often<br>399 (37)      |
| 'When I left the hospital I understood what I was supposed to do to take care of myself.'                                             | Agree/strongly agree<br>970 (91) |
| 'When I left the hospital, they took my preferences into account when they decided on the plan for my care.'                          | Agree/strongly agree<br>797 (75) |

CHF, congestive heart failure; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease; ESRD, end-stage renal disease; GFR, glomerular filtration rate.

responses provide specific examples of what has been described as 'post-hospitalization syndrome'—a condition of elevated, generalised risk for poor health outcomes within 30 days of discharge due to patients' inability to care for themselves, manage their affairs and recover from their hospitalisation that leads to readmission shortly after discharge.<sup>24 25</sup> Others have also suggested that most readmissions may be more attributable to such patient-level factors than hospital-level factors including the quality or intensity of discharge care.<sup>26</sup> In contrast to studies that have quantified hospital-specific characteristics and processes of care, our mixed-methods results underscore the importance of patient-reported and patient-specific

challenges or barriers to post-discharge recovery. Addressing these challenges requires both better anticipation of these issues and preparation of patients while still in the hospital; it will also require better monitoring of conditions and ongoing assistance to enact discharge plans after discharge. Such changes may require new post-discharge roles and programmes for physicians<sup>27</sup> and hospitals<sup>28</sup> that challenge the traditional paradigm for 'ownership' of patient concerns based on episodes of care as part of a larger effort to understand and improve continuity of care in the 21st century.<sup>29</sup>

Additionally, we observed significant variation in the types of barriers encountered by patients and

**Table 3** Patient-centred readmission factors from multiple-choice questions

|                                                                                                                                                                                                                                                                                                                          | <b>558<br/>(52%)</b> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------|
| <b>Total sample that reported <math>\geq 1</math> difficulty from multiple-choice questions</b>                                                                                                                                                                                                                          |                      |
| <i>Difficulties and representative quotations (overarching themes in parentheses)</i>                                                                                                                                                                                                                                    |                      |
| 1. Difficulty following diet (self-management)                                                                                                                                                                                                                                                                           | 235 (22%)            |
| It was difficult for me to eat right. I ate what I had.<br>I didn't feel like going shopping...I'm on disability, and I needed to wait for my check to get food.                                                                                                                                                         |                      |
| 2. Difficulty with transportation to follow-up care (discharge planning)                                                                                                                                                                                                                                                 | 209 (20%)            |
| I couldn't get to my doctor appointments. I have to wait 3 days for Mass health transportation, and my appointments were scheduled too soon after discharge to get an appointment with my ride.                                                                                                                          |                      |
| 3. Difficulty taking medications correctly each day (medication safety)                                                                                                                                                                                                                                                  | 192 (18%)            |
| I don't sleep in the hospital, so when I get home, I sleep more...and I end up sleeping through times I'm supposed to take my meds...They give you a lot to do when you leave the hospital. Sometimes it's difficult to follow the discharge instructions they give you.                                                 |                      |
| 4. Difficulty with inadequate social support (social support)                                                                                                                                                                                                                                                            | 160 (15%)            |
| I didn't have a support system when I went home...a nurse came twice a week, but only took my vitals. I wasn't able to cook because I was still weak...I just needed more help...My discharge was excellent. I understood everything, they explained it well too. I just wasn't able to care for myself when I got home. |                      |
| 5. Difficulty contacting doctor if needed (Self-management)                                                                                                                                                                                                                                                              | 149 (14%)            |
| When I left, they said I needed tests by my doctor. But I didn't know which doctor...so they didn't get done and I wound up in the hospital a few days later.                                                                                                                                                            |                      |
| 6. Difficulty with basic needs such as food, shelter, utilities and the like (other issues)                                                                                                                                                                                                                              | 117 (11%)            |
| I have a hard time staying warm at home...and air/climate (temperature) is a trigger for my pain.                                                                                                                                                                                                                        |                      |
| 7. Difficulty with alcohol or drugs (other issues)                                                                                                                                                                                                                                                                       | 73 (7%)              |
| I have sobriety problems. I'm enrolled in an alcohol recovery program...but it hasn't started yet and I have conflicts with their timeframe.                                                                                                                                                                             |                      |

caregivers after discharge; no single problem was endorsed by more than 22% of the total sample and many patients experienced several problems. Taken collectively, our findings suggest that from the patient's perspective, many transitions might be improved through multi-component 'bridging' interventions<sup>30</sup> to increase support for recovery in the post-acute phase when these problems emerge. The lack of anticipatory guidance reported by patients in our study also suggests potential knowledge gaps for discharging providers. Hospital providers may need to reframe discharge education to probe more deeply into patient and caregiver skillsets and resources and include more anticipatory guidance when skills or resources are lacking. On the other hand, several recent trials that incorporated robust post-discharge engagement interventions have illustrated the difficulty of impacting readmission rates, particularly in high-risk populations.<sup>28 31 32</sup> Given the wide range of problems patients face after discharge from the hospital, it may be that greater engagement and support in the community (rather than in the hospital) are also needed to further impact readmission rates.

Our findings have important clinical and policy implications. While patients reported high levels of overall engagement and satisfaction with the discharge process, this conflicted with their perception of not being adequately prepared for issues that might raise post discharge. These findings support the notion that future efforts to improve transitions should focus on patient self-management, clinical and social support after patients leave the hospital. Recently, several successful interventions to create partnerships between hospitals and communities have emphasised guidance and support from community members outside the hospital.<sup>33 34</sup> These efforts should start while patients are still in the hospital, but our results support the idea that at least as much emphasis should be placed on post-acute support. Indeed, a recent systematic review and meta-analysis of readmission interventions showed programmes supporting patient capacity for self-management and more comprehensive post-discharge support were more effective than programmes that neglected these areas.<sup>35</sup> From a policy standpoint, initiatives funded through Medicare Community-based Care Transition Program<sup>36</sup> have

**Table 4** Patient-centred readmission factors from open-ended questions

| Total sample that reported difficulties in open-ended questions only*                                                                                                                                                                 | 508 (48%) |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------|
| <i>Sub-themes and representative quotations (overarching themes in parentheses):</i>                                                                                                                                                  |           |
| No problems (patient uncertain what went wrong) or new problem (other issues)                                                                                                                                                         | 171 (34%) |
| I followed all the instructions. The readmission was a surprise to me.<br>I don't know what happened. I feel I got all the care I could need.                                                                                         |           |
| Persistence or progression of disease or uncontrolled symptoms (self-management)                                                                                                                                                      | 156 (31%) |
| My organ doesn't cooperate; nothing to do with the plan, it's just chronic.<br>My disease is progressing, there's only so much you can do to prevent this.                                                                            |           |
| Discharged too soon (discharge planning)                                                                                                                                                                                              | 39 (8%)   |
| I left prematurely; I didn't realize the seriousness of what was going on.<br>They let me go too soon; maybe I should have stayed here longer.                                                                                        |           |
| Poor quality care before discharge such as misdiagnosis, miscommunication (hospital care quality)                                                                                                                                     | 32 (6%)   |
| If they did a CT scan last time, these things wouldn't have developed.<br>If they had listened to me, I wouldn't keep coming back with infections.                                                                                    |           |
| Transition care issues such as poor instructions, continuity or home health (care coordination)                                                                                                                                       | 31 (6%)   |
| They didn't give me proper instructions about how to take care of my IV.<br>I was handed off to nobody...I feel like no one really oversees everything.<br>I wasn't satisfied with the visiting nurse; she didn't show up as planned. |           |
| Medication issues including adverse effects or ineffective medications (medication safety)                                                                                                                                            | 27 (5%)   |
| I had an allergic reaction to the antibiotics they prescribed me last time.<br>Stronger meds or higher dose would've kept me out of the hospital longer.                                                                              |           |
| Non-adherence to discharge plan such as missed treatment or appointments (self-management)                                                                                                                                            | 19 (4%)   |
| I didn't take care of myself; didn't follow-up as good as I should have.<br>I had to wear a vest but I didn't feel comfortable so I refused.                                                                                          |           |
| Financial or insurance issues (could not afford meds or recommended diet) (discharge planning)                                                                                                                                        | 10 (2%)   |
| My prescriptions didn't allow generics, so I couldn't afford my meds.                                                                                                                                                                 |           |
| Functional issues (other issues)                                                                                                                                                                                                      | 7 (1%)    |
| I thought I was ready to go home but I had difficulty climbing stairs.                                                                                                                                                                |           |

\*These 508 patients reported no difficulties in multiple-choice questions from [table 2](#).

shown early promise. Expansion of similar community-hospital partnerships could help refine evidence for such approaches.

Our study has several limitations. First, although we used a randomisation process to select our sample of readmitted patients from the general pool of readmissions at each hospital, our sample is not a perfect representation of this larger pool. For example, our mean age was 56 years which is slightly lower than other readmission studies from hospitals like ours which range from 58 to 61 years.<sup>37–39</sup> Our lower age is likely due to our exclusion of patients with cognitive impairment and limits the generalisability of our findings to these patients. Moreover, our study adds important understanding for younger but medically complex readmitted patients and underscores the need to study patients with cognitive issues and their caregivers more

closely in future research. Second, the patient perspectives we captured may be subject to positive response bias, given that the interviews occurred in the inpatient setting at the time of readmission. Nonetheless, we felt this approach was necessary to understand the events immediately preceding readmission and to avoid recall bias with interviews conducted after discharge from that hospitalisation. Third, we did not directly ask patients whether they felt ready for discharge from the index admission; however, recent studies have shown no correlation with patients' perceived readiness for discharge<sup>40 41</sup> and we were more interested in exploring specific, underlying reasons for patient concerns about their transition. Moreover, patient responses to our open-ended questions suggest that many post-discharge issues may not be readily apparent or predictable at time of discharge, even in retrospect.

Finally, we excluded patients who did not speak English which limits generalisability to these populations. On the other hand, a large randomised controlled trial focused on language-concordant interventions in high-risk patients and found that language issues did not reduce readmissions<sup>33</sup> and an in-depth qualitative study of a subset of these patients also did not identify language issues as a key barrier to recovery,<sup>11</sup> which suggests the effects of language may be more distal or cumulative than the narrow 30-day readmission window. Future research should compare and contrast the experience of those that have and those who do not have experienced readmission to gain insights into how patients with similar challenges experience different outcomes. Similarly, future studies should explore the extent to which patient perceptions differ from provider perceptions surrounding transitions of care and readmissions.

In conclusion, readmitted patients in this multi-site study reported high understanding of discharge plans but low perceived anticipatory guidance for resolving common barriers to recovery after discharge. Anticipatory efforts to support patients with difficulties after discharge may improve transitions and reduce readmissions.

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**Part 1. Interview Tool: Patient perspectives on reasons for readmission**

“My name is <<>> and I am working with a team which is trying to understand why patients come back to the hospital after they go home. I’d like to ask you some questions about how things went after your last hospitalization, and what ideas you have about how things might have gone better.”

Who was interviewed? Patient: <sub>1</sub> Caregiver: <sub>2</sub> Both: <sub>3</sub>

1. Did you have a follow-up visit scheduled to see a doctor or nurse before you came back to the hospital? YES <sub>1</sub> NO <sub>2</sub> Don’t know <sub>3</sub>
2. Were you able to attend your scheduled visit (not an urgent care visit) before you came back to the hospital? YES <sub>1</sub> NO <sub>2</sub> NO VISIT SCHEDULED <sub>3</sub>

“Now, I would like to ask you some questions about your communication with the doctors and nurses who took care of you when you were getting ready to leave the hospital last time.”

3. When you were getting ready to leave the hospital last time, how often did they give you enough time to say what you thought was important?
  - Always     Often     Sometimes     Rarely     Never     Don’t know or refused
4. When you were getting ready to leave the hospital last time, how often did you feel pressured by them to have a treatment you were not sure you wanted?
  - Always     Often     Sometimes     Rarely     Never     Don’t know or refused
5. When you were getting ready to leave the hospital last time, how often did they ask if you might have problems actually doing the recommended treatment (for example, taking the medication correctly)?
  - Always     Often     Sometimes     Rarely     Never     Don’t know or refused

“Now, I’m going to read some statements about when you left the hospital last time and ask if you agree or disagree”

6. “When I left the hospital, I understood what I was supposed to do to take care of myself.”
  - Strongly agree     Agree     Disagree     Strongly disagree     Don’t know or refused
7. “When I left the hospital, they took my preferences into account when they decided on the plan for my care.”
  - Strongly agree     Agree     Disagree     Strongly disagree     Don’t know or refused

“Next I would like to ask you about some problems that you might have faced after you left the hospital last time. I will read some more statements and ask if you agree or disagree.”

8. “After I left the hospital, I had difficulty taking each of my medications correctly every day.”
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  - Don’t know or refused
  
9. “After I left the hospital, I did not know how to contact my doctor if I needed to.”
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  - Don’t know or refused
  
10. “After I left the hospital, I had difficulty with transportation to my doctor’s appointment or other tests.”
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  - Don’t know or refused
  
11. “After I left the hospital, I had difficulty meeting basic needs such as food and shelter.”
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  - Don’t know or refused
  
12. “After I left the hospital, I had difficulty following the diet my doctor recommended to keep me healthy.”
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  - Don’t know or refused
  
13. “After I left the hospital, I did not have enough support from friends, family, neighbors and/or others who care for me, to follow the hospital discharge instructions and recover from my illness.”
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  - Don’t know or refused
  
14. “After I left the hospital, I had problems related to drinking alcohol or using drugs.”
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
  - Don’t know or refused

“I’d also like to ask you a few questions about your use of technology to communicate with your doctors or nurses in the last 12 months”

15. In the last 12 months, have you looked up health information on the Internet?
  - Yes
  - No
  - Don’t know or refused
  
16. In the last 12 months, have you (or someone who cares for you) refilled one of your prescriptions on the Internet?
  - Yes
  - No
  - Don’t know or refused
  
17. In the last 12 months, have you (or someone who cares for you) scheduled one of your medical appointments on the Internet?
  - Yes
  - No
  - Don’t know or refused

18. In the last 12 months, have you (or someone who cares for you) communicated with a healthcare provider about your health using email or the Internet?

- Yes                       No                       Don't know or refused

19. In the last 12 months, did you have access to the Internet at home?

- Yes                       No                       Don't know or refused

**Part 2. Discussion Guide: Patient perspectives on reasons for readmission**

20. In your own words, can you tell me more about any problems or difficulties you've had getting better or staying healthy since you left the hospital last time?

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21. Is there anything you think might have helped you stay out of the hospital this time?

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22. Is there anything else you'd like to tell me about returning home after leaving the hospital last time?

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