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“I Need my Own Place to get Better”: Patient Perspectives on the Role of Housing in Potentially Preventable Hospitalizations

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Abstract

Objective—To analyze patient perspectives on the role of housing in their potentially preventable hospitalization.

Methods—Individuals admitted with cardiovascular-or diabetes-related diagnoses (n = 90) in a major medical center in Hawai'i completed an in-person interview eliciting patient perspectives on key factors leading to hospitalization. Using the framework approach, two independent coders identified themes. This study focused on housing-related findings.

Results—Overall, 23% of participants reported housing as a precipitating factor to their hospitalization, including 12 with no regular place to stay. Four housing-related themes emerged: challenges meeting basic needs, complex chronic care management difficulties, stigma and relationship with provider, and stress and other mental health issues.

Discussion—Almost 25% of patients identified housing as a key factor to their hospital stay. Patient-reported themes highlight specific mechanisms by which housing challenges may lead to hospitalization. Addressing housing issues could help reduce the number and associated cost burden of preventable hospitalizations.

Keywords

Housing; preventable hospitalizations; patient perspectives; diabetes; heart failure

In the United States, 10% of all hospitalizations are considered potentially preventable, defined as admissions for acute or chronic illness complications that might not have required hospitalization with successful management in primary care.¹ Congestive heart failure (CHF) and diabetes mellitus (DM) are leading causes of these potentially avoidable hospitalizations.¹ Often termed “ambulatory care sensitive conditions,” these hospitalizations are the focus of considerable research and policy attention.”^{1–3}

Studies identifying reasons for preventable hospitalizations are critical to the development of interventions to reduce the number of future admissions, thus reducing costs and improving outcomes for patients.⁴ Currently, most preventable hospitalization research focuses on administrative and hospital discharge data.⁵ These studies typically lack information on key socio-demographic details that often play a critical role in hospital admissions.^{6–10}

Access to adequate and stable housing is an understudied socio-demographic factor that may affect the likelihood of a preventable admission. A study by Wicks, Trevena, and Quine showed that self-efficacy, defined as the perceived ability to perform diabetes management behaviors, decreases as housing instability increases.¹¹ Other prior research shows that inadequate or unstable housing conditions produce negative health effects,^{12–19} including increased heart disease, obesity, and DM.¹⁴ Furthermore, challenging housing conditions can directly impede healthy behaviors such as exercising regularly¹⁵ and eating a nutritious diet.¹⁶

Mechanisms illustrating how housing conditions relate to potentially preventable hospitalizations are not currently well-studied in the literature. This study focused in detail on the housing-related findings of a larger project²⁰ on patients' perspectives of their pathways to DM-and CHF-associated preventable hospitalizations in Hawai'i. Through interviews with individuals reflecting Hawai'i's population mix, including Native Hawaiians and Other Pacific Islanders (NHOPI), Filipinos, Other Asians, and Whites, we collected and analyzed patients' perspectives on factors leading to their hospital stay in order to gain an understanding of the precipitating factors and specific challenges patients may have encountered prior to being hospitalized. To our knowledge, this is the first study to explore patient perspectives on the relationship of housing to potentially preventable hospitalizations.

Methods

Study site

The study was conducted at The Queen's Medical Center (QMC), the largest hospital in Hawai'i and the primary tertiary medical referral center for the Pacific Basin.

Overall study sample

Adults hospitalized at QMC from June 2013 to December 2014 for a DM-or CHF-related preventable hospitalization were considered. Agency for Health Care Research and Quality (AHRQ) guidelines for identifying preventable hospitalizations for acute care-sensitive conditions were used.⁵ Inclusion criteria were admission diagnoses for CHF, uncontrolled DM, short-term DM complications, long-term DM complications, and lower-extremity DM-related amputations. Race and ethnicity were self-reported. The study focus was on the major racial/ethnic groups in the state (Japanese, Chinese, Filipino, White, Native Hawaiian, and Other Pacific Islanders), who are understudied. Other racial/ethnic groups, such as African Americans and Hispanics, which in total constitute less than 10% of Hawai'i's population, were not included.

Patients with DM or CHF who met study inclusion for hospitalization type and race/ethnicity were identified at the time of hospital admission by patients' attending physicians or advance practice nurses who were part of the care team. A clinically trained nurse researcher then obtained permission from the patient's attending physician and, if given, further screened each patient to confirm study eligibility in a face-to-face interview. Patients were excluded if they were 1) unwilling to participate in semi-structured interview and answer survey questions; 2) in the intensive care unit; 3) clinically unstable; 4) pregnant; 5) suffering memory loss or unable to participate in interview; 6) a non-Hawaii resident; or 7) a resident of nursing home, hospice, prison, or other similar institution. If eligible, informed consent for study participation was obtained.

A large portion of individuals identified as potentially eligible by providers (n = 393) were ineligible for the study interview (n = 238). The most common reasons were altered mental status, including dementia (n = 82), limited English proficiency (n = 76), and being too ill to participate (n = 34). In September 2014, we reached thematic saturation for Native Hawaiians and began to exclude this group from our interview study (n = 33). Among those otherwise eligible, 30 refused to participate, primarily because they were not interested in the topic. An additional two individuals were deemed ineligible for study inclusion after interview completion; one admission was for a congenital heart issue, not a preventable condition, and one was for chronic obstructive pulmonary disease, not a study focus. Thus, the final interview sample was 90. More details on the overall study can be found elsewhere.²⁰

Data collection

After obtaining informed consent, the nurse researcher conducted an approximately 45-minute long, face-to-face interview, including a questionnaire and semi-structured interview with closed and open-ended questions to elicit patient stories and perspectives on reasons for their preventable hospitalization. (An abridged version of this questionnaire including the relevant questions is available from the authors upon request.) The primary housing-related question from the questionnaire was, "Do you have a regular place to stay when you are not in the hospital?" followed by "If not, where do you live?" Open-ended questions were asked to garner patient perspectives on factors precipitating their hospitalization, including: "Give me a sense of what was going on at home and with your health before you came to the hospital," "What do you think happened with your heart problem/diabetes that you got sicker?" and "Is there anything different that could have been done to prevent you from coming to the hospital?" With patient permission, participant medical records were reviewed by the nurse researcher to obtain baseline demographic information (e.g., age, gender, ethnicity, and insurance) and key clinical information (e.g., vital signs, cardiac and diabetes history, laboratory values, and comorbidities).

Data were collected and managed using the Research Electronic Data Capture (REDCap) program hosted by the University of Hawai'i.²¹ Wi-Fi-enabled iPad tablets were used to conduct interviews, record interviews, and upload data to REDCap. All patients received a \$20 drug store gift card for study participation.

Qualitative analysis

Two independent coders with expertise in chronic diseases and NHOPI communities reviewed interview transcripts, recordings, and the nurse researcher's notes. Coders independently reviewed each interview, then resolved discrepancies through discussion to create one consensus coding per participant.^{22–24} Using the framework approach^{25–26} the coders identified patterns of patient-reported reasons for their preventable hospitalization, specifically focusing on precipitating factors previously identified in other research (e.g., transportation, medication adherence, access to primary care, and housing),²⁷ as well as emerging themes.

Housing sample

For this portion of the larger study, we were particularly interested in understanding the demographic and social context of those with housing-related issues. We merged those identified to have housing-related issues from the questionnaire (n = 12) and those additionally reporting housing-related factors in qualitative thematic data (n = 9). Thus, a “housing sample” was drawn from those who responded that they had no regular place to stay in response to the questionnaire (12 patients), plus those who relayed a housing-related theme in their story (all 12 with no regular place to stay plus an additional nine patients). This housing sample allowed us to compare the characteristics of those who identified housing-related concerns in some fashion with the overall sample.

Using patient stories and the consensus coding for each participant, housing issues were categorized into three distinct groups: those who were homeless (e.g., did not have a place to stay, lived on the beach, or lived in a car) (n = 12); those who experienced housing instability or were unstably housed (e.g., living in transitional housing, friend, or family member's house, or regularly moving between residences) (n = 6); and those who were stably but inadequately housed (e.g., had their own place but living conditions and/or facilities were poor) (n = 3).

Results

Overall sample

As seen in Table 1, 56% of 90 interviewees were NHOPI, 19% were White, 13% were Other Asian, and 12% were Filipino. Of the 90 participants in the overall sample, 71% were working age (18–64 years), 33% were female, and the majority (58%) had family income less than \$40,000. Even so, participants had good access to care: 90% were insured and 88% had a usual source of care. Twenty-nine percent of the hospitalizations were CHF-related, 34% were DM-related, and 37% were both DM-or CHF-related; more than half of the participants (65%) had been previously hospitalized for the same problem.

Housing sample

Of the 90 individuals who were interviewed, 21 participants (23%) disclosed housing-related issues as precipitating factors to their preventable hospitalization. In our descriptive comparison (Table 1), it is interesting, but perhaps not surprising, that a greater proportion of the sample reporting a housing-related concern had concurrent depression and substance use

based on relevant fields in their electronic records, and a challenging life event (e.g., arrest, divorce, death in the family) compared with the overall sample.

Housing themes

For the subset of 21 patients, we identified four housing-related themes from the open-ended interviews and patient stories about precipitating pathways to their hospitalization: 1) challenges meeting basic needs, 2) complex chronic care management difficulties, 3) stigma and relationship with provider, and 4) stress and other mental health issues. Subthemes in each category were also identified. Representative quotations describe themes and subthemes in greater detail below; complete quotations are available upon request from the authors.

Theme 1: challenges meeting basic needs

Limited access to healthy foods: Homeless or unstably housed participants said they had limited access to fresh produce and healthy foods at the places they lived. In shelters or transition homes most meals consisted of high-salt, canned foods which opposes healthy dietary guidelines for CHF patients.²⁸ One 56-year old woman with CHF conveyed how living in a transition home negatively affected her diet. She said, “I barely ate where I’m staying at. . . . I cannot eat a lot of salt and most of the food [there] is canned and salty.” Similarly, a homeless 56-year old male with CHF who lived on the beach in his car recounted, “I go to the churches to get food, but all the food over there is canned goods.”

Lack of shelter: Concerns over a dearth of shelter often took precedence over self-care. One 49-year old male participant with DM succinctly related the importance of safe and stable housing when he said, “It’s hard to know how to take care of yourself when you don’t have a safe place to live.” When asked if having shelter would have prevented her hospitalization, a homeless 50-year old female with DM said, “Then we have a place where we can entrust that our stuff is safe . . . yes, it would make a lot of difference.”

Lack of access to clean water: Poor access to clean running water was an identified barrier for the homeless population. One participant, who endured various DM-related amputations and was readmitted multiple times in the previous 12 months for a recurring infection, discussed significant challenges of being homeless and caring for her foot ulcer. For this 50-year old female, being homeless negatively affected her ability to maintain sufficient wound care to prevent further infection. She explained, “Because we are homeless, it’s hard to get clean running water. I do carry saline . . . and I use it . . . when I don’t have any [clean water].”

Theme 2: complex chronic care management difficulties

Inability to follow medical directives: Challenging housing conditions left individuals unable to follow medical advice upon discharge from the hospital. This issue was particularly prevalent with CHF patients because proper disease management requires strict regulation of salt and fluid intake. Yet, for many participants, there was a distinct mismatch between clinical advice from doctors and their actual circumstances at home. Regarding fluid intake, a 57-year old male with CHF reported living in a rented apartment with a very

strict land-lady who would not install air conditioning or overhead fans despite his health problems. He described difficulty in regulating his fluid intake, and a tendency to overdrink especially during hotter summer months. He said, “So they [doctors] tell me, ‘Don’t drink water.’ I tell them, ‘You try not drink water where I live’ . . . I cannot live like that.”

Problems going to provider appointments: Regular follow-up appointments with physicians are essential to chronic care management and avoiding preventable hospitalizations. Despite being stably housed, this 68-year old woman with CHF conveyed that faulty or inadequate facilities at her apartment complex sometimes resulted in missed doctor appointments. For her, regular visits with a psychiatrist facilitated proper management of her depression which, if left unaddressed, often prevented adequate self-care at home. She said, “I had an appointment with a psychiatrist, but . . . our elevator broke . . . so anyway I couldn’t go anywhere.”

Challenges with dietary restrictions: Inadequate facilities and unstable housing conditions were barriers for patients with strict dietary restrictions. One 65-year old male participant with DM shared that, while previously hospitalized, the electricity in his house was shut off. Upon returning home he could not maintain a healthy diet, which he identified as the main precipitating factor to his current hospital stay. He said, “I cannot eat . . . my diet. No electricity, nothing . . . that’s why I wanna get out of that area already cause almost I die so I don’t need that.” Similarly, another male with CHF indicated that insufficient kitchen space and cooking facilities at home prevented him from eating healthily. He attributed his current hospital stay for CHF-related shortness of breath to his poor diet. This 57-year old said “I’m just running off of like a toaster oven . . . so I don’t have a full blown kitchen, which I wish I did because I love to cook.”

Managing medications: Both DM and CHF are highly regulated by medication, and effective self-care to prevent hospitalization hinges on appropriate medication management. However, numerous interviewees reported that unstable housing often deterred and even prevented their adherence to their medication regimens. This was especially pertinent for homeless diabetic patients who lacked refrigeration to store their insulin. A 44-year old male participant with DM told us that, after getting kicked out of his sister’s home, he slept at a bus stop the week prior to hospitalization. He shared that his unstable housing, constant movement between the homes of friends and family, and eventual homelessness prevented him from properly managing his medications. He said, “I just sleep at the bus stop. I just need to find me one shelter where I can take my medications . . . so that’ll be nice to be in one shelter . . . because it’s not ok when you’re homeless and . . . not taking your medication.”

Combination issues: transportation and medication, diet and medication: Many participants experienced multiple barriers to DM and CHF disease management outside the hospital. One 65-year old male with both DM and CHF shared that living so far from his doctor’s office and lacking transportation resulted in him not replenishing medications and being hospitalized for shortness of breath. He said, “I stay with friends but there’s no transportation there. I have no ride . . . I gotta change doctor . . . get one different place soon

where I can get transportation.” Another participant with both DM and CHF discussed the effects of unstable housing on her health: prior to hospitalization, she had little control over her diet, schedule, and environment. This 51-year old female said, “[It was] a combination of things. From me moving house to house I cannot keep myself on a set schedule to where the times I eat, the times I take my medication, the times I sleep . . . it has to be the convenience of where I stay.”

Theme 3: stigma and relationship with providers

Stigmatization of homelessness: Participants reported feeling stigmatized by providers due to their housing status. A 49-year old male with CHF who was homeless since his mid-30s expressed deep shame and depression associated with perceived stigma to such an extent that it prevented him from accessing and utilizing health care for many years. He said, “If the person wouldn’t be so judgmental . . . but how people look at me when you tell them you’re homeless or they find out, it’s a totally different look.”

Provider-patient relationship: Some participants described experiencing stigma related to homelessness that negatively affected their relationship with their doctor. A 52-year old homeless male with CHF, when asked about his relationship and trust with doctors, said, “I felt like at one point the medical care over [there], I wasn’t being treated fairly. The doctors . . . didn’t seem all that supportive . . . yeah like when you talk to them, they didn’t make me feel comfortable, they used to make me feel bad.” Another participant with CHF reported that feeling stigmatized often prevented him from visiting his doctor for routine maintenance of his chronic conditions. This resulted in a fast decline to decompensated heart failure at such a young age. This 49-year old male said, “A lot of people, they’re quick to judge you . . . yeah it kind of interferes with the health care that I get. Because when they found out I’m homeless and I do drugs, that’s when they, uh I didn’t receive any medical.”

Theme 4: Stress and other mental health issues

Disability and discrimination: A few elderly participants with physical disabilities reported that housing-related stress and perceived discrimination played a role in their hospitalizations. A 68-year old female with CHF, who relied heavily on a walker and could not drive, reported that her housing situation became precarious due to her roommates not wanting to cope with her physical impairments. During her hospitalization, she was worried about finding new and stable housing. She also shared that her additional stress was making her sicker. She said, “Well I’m mainly concerned with . . . I don’t think my roommates want me there anymore because I am handicapped . . . and they’re pressuring me into trying to find a place and it’s not like I can . . . jump in a car and go look at an apartment.”

Financial stress: high cost of living: Financial strain related to the high cost of living in Hawai‘i was another source of stress for those reporting housing-related concerns. A 45-year old male with DM, reported that his health was secondary to his other responsibilities. After his father died he became the sole provider and was financially responsible for his two disabled siblings and elderly mother. Prior to his hospitalization, this patient was paying \$181.20 per day (almost \$5,500 per month) for a two-bedroom apartment in a local hotel. He thought the additional stress from the financial burden of providing housing for his entire

family negatively affected his health. He said, “At home I have a lot of stress for paying for things where I live, it’s a hotel room . . . I’m actually paying for the room while I’m here [in the hospital] . . . my credit card still pays for the room at the hotel.”

Lack of control of environment: Many interviewees spoke of generalized hardships and feeling helpless and sad because of a lack of control of their environment. A 65-year old male with both DM and CHF shared a story about his situation: prior to hospitalization, his wife died, his son lived in the continental United States, and his daughter was in jail, so they could not help care for him. During the interview he expressed a need for better housing conditions, and identified the loss of control over his environment as the predominant precipitating factor for his current hospitalization. When asked what he felt he needed to get better, this participant responded, “My own place, period. Tell you the truth that’s what it is, my own place and that’s it . . . I don’t think I going get better if I keep going to that [other] place.”

Another participant spoke of her inability to perform self-care because she was constantly in a state of flux. This 51-year old female with both DM and CHF said that sometimes her health status directly depended on her housing situation. She thought that her lack of control and associated stress of trying to find a place to stay played a role in her hospitalization. When asked why she was feeling stressed she responded, “Because I was staying with my sister . . . then I had to move out of her place . . . move [in] with my nieces . . . [then] I moved out . . . because she wanted to beat me up . . . [I want to] stay someplace that I can call my own, [so] I don’t have to live under other people’s rules.”

Challenging life events: Many interviewees had multiple social needs (e.g., inadequate housing, no transportation, and financial stress). Yet, adverse housing-related events were distinctly recognized as significant sources of overall stress, contributors to a decline in health, and subsequent hospitalization. When our nurse researcher asked a 50-year old male participant with both DM and CHF to recount events a month prior to his hospitalization, he said he was illegally evicted and denied access to his belongings and medications. He said, “I was scrambling for a place to live and I got locked out quite abruptly, an illegal lock-out, which meant that my prescriptions were on one side and I was on the other [side] of the padlock.”

Discussion

To understand precipitating factors and pathways to preventable hospitalizations for DM and CHF, we interviewed 90 patients to hear their stories. This study provides detailed insight into patient-identified mechanisms and pathways describing how housing can play a role in preventable hospitalizations. Almost a quarter of participants (23%) identified either a lack of housing or unstable or inadequate housing as a key precipitating factor. Emergent themes describing these pathways to preventable hospitalizations include challenges meeting basic needs, complex chronic care management difficulties, stigma and relationship with provider, and stress and other mental health issues.

The first two themes pertain to a patient's ability to self-care and manage their own disease outside of the hospital. Previous research identified barriers to self-care such as doctor-patient incongruence with instructions, poor nutrition and unhealthy diet, medication non-adherence, lack of trust with providers, and mental illness.²⁹⁻³¹ Patient stories from this study provided specific examples of self-management issues arising from housing situations. Fluid and salt intake was affected by an inability to cool their apartments. Individuals with DM reported medication non-adherence due to a dearth of refrigeration facilities for insulin storage. Due to being "too worried about housing," many interviewees experienced multiple barriers and could not prioritize health, nor take care of themselves properly.

Other important themes from this study link housing-associated psychosocial factors with preventable admissions. Prior research shows that homeless people face stigma, discrimination, and heightened stress, and that these types of psychological factors affect patient outcomes.³²⁻³⁵ Patients from this study reported that perceived stigma and discrimination related to homelessness presented in daily life and during interactions with health care professionals. Some even mentioned not receiving needed services and ignoring health problems because they felt ashamed of their homeless status. Study participants also highlighted the chronic stress associated with homelessness or unstable housing as a precipitating factor for worse health states and eventual hospitalization. This coincides with a recent study's findings that the social determinants of mental health primarily affect people by triggering the body's stress response into overdrive and hyperactivity, altering one's psychology and physiology in a negative way and producing illness.³⁶ To ameliorate the effects of chronic stress on our bodies, we must develop interventions that target these social determinants or "the causes of the causes" of illness, including mental health.³⁷

For many participants, their time in the hospital indicated a "turning point" in their journey towards better health, suggesting that hospital stays can provide a great opportunity for intervention. Studies show that a multidisciplinary and team-based model can be successful in improving patient outcomes and preventing hospital stays and future readmissions.³⁸⁻⁴⁰ Cooperation between clinical and social service providers affords a more integrative approach to addressing social factors, and enhances the clinical team's ability to address specific non-medical needs such as housing; this could result in shorter hospital stays and preventable readmissions. Furthermore, by using this team-based approach in the hospital, and then carrying the concept over to the outpatient setting by involving community health workers, case managers, and even community members and leaders, we might be able to offer patients with complex chronic conditions and social situations wraparound care.

A recent study reported that after receiving supportive housing, there were significant reductions in overall healthcare expenditures for formerly homeless individuals.⁴¹ Cost reductions were primarily driven by decreased emergency care utilization and decreased hospital inpatient stays.⁴¹ Furthermore, these cost savings did not occur at the expense of quality; respondents who received supportive housing provisions reported improved access to care, stronger relationships with primary care providers, and better outcomes.⁴¹ Building patient-centered, culturally appropriate, and relevant discharge instructions and care plans for patients leaving the hospital will likely reduce readmissions and healthcare costs. Yet,

these strategies would not be well-defined without understanding the underlying pathways to these preventable hospitalizations.

Study findings should be viewed in light of its limitations. The study population is not fully representative of all people with preventable hospitalizations. This was not a randomly drawn population from this hospital, as we focused on diversity across the largest racial/ethnic groups in Hawai'i. Additionally, many participants were ineligible because of limited English proficiency, dementia, or altered mental status. These groups might have challenges distinct from those found in this study. As an exploratory qualitative analysis, this study is limited by its inability to test hypotheses or draw conclusions about causality between housing and DM-and CHF-related preventable hospitalizations. Finally, this study's sample was selected from one major medical center in an urban area and may not be generalizable to the entire state of Hawai'i nor to the continental United States.

Conclusions

Interventions may need to be aimed at reducing preventable hospitalizations by focusing on underlying social issues like housing. Addressing these patient-identified factors can increase understanding of preventable hospitalizations and improve outcomes for patients with DM and CHF.

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Table 1

Study demographics by those reporting housing-related issues and the total sample

| | Reported housing- related issues n (%) 21 (23.3) | Total sample n (%) 90 (100) |
|---|---|--|
| Race/Ethnicity | | |
| Asian | 1 (4.8) | 12 (13.3) |
| Filipino | 4 (19.1) | 11 (12.2) |
| Native Hawaiian/Pacific Islander | 11 (52.4) | 50 (55.6) |
| White | 5 (23.8) | 17 (18.9) |
| Education | | |
| Less than High School | 8 (38.1) | 20 (22.2) |
| High School Grad | 12 (57.1) | 66 (73.3) |
| College Grad | 1 (4.8) | 4 (4.4) |
| Age Group | | |
| Working Age (18–64) | 16 (76.2) | 64 (71.1) |
| Older (65+) | 5 (23.8) | 26 (28.9) |
| Female Gender | 6 (28.6) | 30 (33.3) |
| Family Income | | |
| under \$40,000 | 13 (61.9) | 52 (57.8) |
| over \$40,000 | 1 (4.8) | 9 (10.0) |
| Missing | 7 (33.3) | 29 (32.2) |
| Insured | 18 (85.7) | 81 (90.0) |
| Has Usual Source of Care | 18 (85.7) | 78 (87.6) |
| Admitted for | | |
| Diabetes | 8 (38.1) | 31 (34.4) |
| Heart Disease | 9 (42.9) | 26 (28.9) |
| Both Diabetes & Heart Disease | 4 (19.1) | 33 (36.7) |
| Previously Hospitalized (at same hospital) for this issue | 14 (66.6) | 55 (65.5) |
| Concurrent Depression | 15 (71.4) | 47 (52.2) |
| Concurrent Substance Use | 8 (38.1) | 30 (33.3) |
| Challenging Life Events | 7 (33.3) | 10 (11.1) |