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'The Thing that Really Gets Me Is the Future': Symptomatology in Older Homeless Adults in the HOPE HOME Study

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### Authors

Bazari, Adam

Patanwala, Maria

Kaplan, Lauren M

et al.

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Corresponding Author: Dr. Margot Kushel, MD

Corresponding Author's Institution: UCSF/San Francisco General Hospital

First Author: Adam Bazari, MS

Order of Authors: Adam Bazari, MS; Maria Patanwala, BS; Lauren M Kaplan,  
PhD; Colette L Auerswald, MD; Margot Kushel, MD

## UNIVERSITY OF CALIFORNIA, SAN FRANCISCO

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SANTA BARBARA • SANTA CRUZ

MARGOT KUSHEL, MD

Professor of Medicine  
Division of General Internal Medicine  
Department of Medicine, ZSFG  
415-206-8655; fax 415 206-5586  
Margot.kushel@ucsf.edu

University of California, San Francisco  
Box 1364 Zuckerberg San Francisco General  
San Francisco, CA 94143

Address for Packages:  
Ward 13 Building 10  
1001 Potrero Avenue  
San Francisco, CA 94110

April 2, 2018

Russell K. Portenoy, MD  
Editor  
Journal of Pain and Symptom Management

Dear Dr. Portenoy:

We are pleased to submit our manuscript entitled, “*The thing that really gets me is the future*’: Symptomatology in older homeless adults in the HOPE HOME study,” to the Journal of Pain and Symptom Management for consideration as an original article. The median age of homeless adults in the US is rising more rapidly than the general population. Older homeless adults experience premature development of age-related conditions and an elevated symptom burden, which is associated with poor health outcomes. We recently published a study examining the prevalence and severity of symptomatology in older homeless adults from the HOPE HOME cohort, a longitudinal study of older homeless adults.<sup>1</sup> In this study, we found that 34.0% of older homeless adults met criteria for moderate-severe somatic symptoms, 57.6% experienced psychological symptoms, 39.6% exhibited loneliness and 26.5% had high regret. This work used symptom scales to highlight the frequency and severity of multidimensional symptoms affecting older homeless adults. However, quantitative scales do not measure the experience or meaning of symptoms. In order to develop appropriate responses to the high prevalence of symptoms among this population, we used qualitative methods in order to understand the experience of symptoms, including etiology, management and coping strategies, and effects on daily life in older homeless adults.

We conducted in-depth interviews with 20 homeless adults, aged 50 and over, using purposive sampling from the HOPE HOME cohort. We recruited from amongst HOPE HOME participants who remained homeless. Using data from the prior HOPE HOME interview, we recruited those who had moderate to severe somatic symptomatology, or who had at least one bothersome somatic symptom and met criteria for at least one of the following: high levels of regret, loneliness, depression, symptoms of PTSD, hallucinations, anxiety or violent impulses. We analyzed the data using grounded theory.



We found four themes: 1) Non-physical symptoms are interwoven with and as distressing as physical symptoms; 2) Individuals attribute symptoms to childhood abuse, manual labor, homelessness, and aging; 3) Symptoms interfere with daily functioning; and 4) Individuals cope with symptoms through religion, social support, and substance use. Given the high prevalence of symptoms among this population, we recommend that medical interventions for this population adapt the principles of palliative care. Shelter-based interventions to reduce symptom burden might include sleeping arrangements that afford privacy and autonomy to individuals, and training staff to avoid stigmatizing language and to promote dignity. Housing interventions should reduce environmental stress and increase opportunities for community-building. Given the high symptom burden in the population, we recommend an approach to symptom alleviation that involves coordinated interventions in healthcare, social services, and housing.

This manuscript has not been previously published and is not under consideration in the same or substantially similar form in any other peer-reviewed media. We presented preliminary results from this analysis at the SGIM annual meeting in Washington DC in 2017. While we have not published any other manuscripts from the qualitative interviews that form the basis of this manuscript, we have published extensively from the HOPE HOME cohort, on topics such as symptoms (as noted above), geriatric conditions, pathways to homelessness, Emergency Department use, tobacco cessation behavior, adverse childhood experiences and factors associated with chronic pain.<sup>2-11</sup> No authors note any conflicts of interest. If accepted, our paper will not be published elsewhere including electronically in the same form, in English or in any other language, without the written consent of the copyright-holder. All authors have approved the manuscript and take responsibility for its content. I will serve as corresponding author. We would like to recommend the following as potential reviewers: Drs. John Song and Lee Ann Lindquist. We thank you for reviewing our manuscript and look forward to hearing from you regarding our submission.

Sincerely,

A handwritten signature in black ink that reads "Margot Kushel MD".

Margot Kushel, MD



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***‘The thing that really gets me is the future’*: Symptomatology in Older Homeless Adults in the HOPE HOME Study**

*Running Title*: Symptomatology in older homeless adults

Adam Bazari, MS<sup>1</sup>

Maria Patanwala, BS<sup>2</sup>

Lauren M. Kaplan, PhD<sup>4,5</sup>

Colette L. Auerswald, MD<sup>1,3</sup>

Margot B. Kushel, MD<sup>4,5</sup>

<sup>1</sup> University of California Berkeley – University of California San Francisco Joint Medical Program, Berkeley, California, USA

<sup>2</sup> University of California San Francisco School of Medicine, San Francisco, California, USA

<sup>3</sup> University of California Berkeley School of Public Health, Berkeley, California, USA

<sup>4</sup> University of California San Francisco /Zuckerberg San Francisco General Division of General Internal Medicine, San Francisco, California, USA

<sup>5</sup> University of California San Francisco Center for Vulnerable Populations, San Francisco, California, USA

Correspondence should be addressed to Margot Kushel MD, Division of General Internal Medicine, UCSF/Zuckerberg San Francisco General, Box 1364, San Francisco, CA 94143-1364.  
Email [margot.kushel@ucsf.edu](mailto:margot.kushel@ucsf.edu)  
(415) 206 8655 (phone)  
(415) 206 5586 (administrative fax)

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## Abstract

**Context:** The homeless population is aging. Older homeless adults experience premature development of age-related conditions and an elevated symptom burden. Little is known about symptom experience among older homeless adults. **Objectives:** To characterize the experience, understanding, and management of physical, psychological, social (e.g. loneliness), and existential (e.g. regret, loss of dignity) symptoms among older homeless adults.

**Methods:** We conducted semi-structured interviews from June 2016 through March 2017 with a purposive sample of participants from the HOPE HOME cohort, a longitudinal study of homeless adults ages 50 and older. We analyzed data between June 2016 and December 2017 via grounded theory methodology, including initial and selective coding, and writing memos.

**Results:** We found four main themes: 1) Non-physical symptoms are interwoven with and as distressing as physical symptoms; 2) Individuals attribute symptoms to childhood abuse, manual labor, the conditions of homelessness, and aging; 3) Symptoms interfere with daily functioning, causing negative changes in personality, energy, and motivation; and 4) Individuals cope with symptoms through religion, social support, and substance use. **Conclusion:** Homelessness causes and exacerbates physical and psychological distress. Interventions should address multiple interconnected dimensions of suffering. Health system interventions for older homeless adults should adapt practices of trauma-informed care and palliative care. Homeless shelters should adopt policies and modifications that increase privacy and autonomy while promoting community-building. Housing interventions should promote community-building. All who work with people experiencing homelessness should avoid stigmatizing language and recognize homeless individuals' sources of strength and coping.

**Keywords:** Symptoms, homelessness, older adults

## INTRODUCTION

Approximately half of single homeless adults today are aged 50 or older, compared to 11% in 1990 (1, 2). Older homeless adults have a higher prevalence of chronic disease, geriatric conditions and symptoms than their age-matched housed counterparts (3, 4). Symptoms (i.e. physical, psychological, social (e.g. loneliness), and existential (e.g. regret, loss of dignity) are negative perceptions of disturbances in normal functioning or sensation (5, 6). Symptom burden refers to the cumulative experience of symptoms including number, frequency, severity, and associated suffering (7).

People experiencing homelessness devote substantial effort to meeting basic needs. Many sleep in uncomfortable and unsafe outdoor locations, or in crowded shelters that they have to leave during the day (8). Thus, homeless adults have more exposure to stressors and fewer opportunities to modify their environment in order to alleviate symptoms (9).

Homelessness and older age are associated with increased symptom burden (4, 10). Homeless adults experience a higher frequency of pain and psychological symptoms compared to other patient populations approaching end of life (11). High symptom burden causes suffering, and is associated with poor health outcomes, including poorer functional status, increased healthcare utilization, and death (12-14). In older adults, high symptom burden is associated with feelings of isolation, guilt, and dependency (15). Loneliness is a risk factor for mental health conditions, poor-self-rated health, functional decline and death (16-18).

Symptom scales, such as the Patient Health Questionnaire 15 (PHQ-15) quantify symptoms. However, they do not measure the experience and meaning of symptoms (19). Little is known about the experience of symptoms among older homeless adults. In order to inform interventions to alleviate symptom-related suffering in this population, we used qualitative



methods to examine symptom experience among homeless older adults, including impacts on their daily activities and functioning, their personal strengths and management strategies, and their views on symptom etiology.

## **METHODS**

### **Study design**

We conducted 20 semi-structured interviews with homeless adults aged 50 and older recruited from the Health Outcomes of People Experiencing Homelessness in Older Middle Age (HOPE HOME) cohort, a longitudinal study of older adults experiencing homelessness (3). Study staff used a teach-back method to obtain informed consent (20). We provided a \$20 gift card for participation. The institutional review board of the University of California, San Francisco (UCSF) approved all study activities.

### **Setting and participants**

Between July 2013 and June 2014, HOPE HOME investigators used population-based sampling techniques to recruit 350 participants from low cost meal programs, recycling centers, and all overnight homeless shelters and locations where unsheltered adults stay in Oakland, CA. Individuals met inclusion criteria if they were age 50 or older, English speaking, able to give informed consent (20), and homeless (as defined by the federal Homeless Emergency Assistance and Rapid Transitions to Housing (HEARTH) Act) (21). Participants self-reported racial/ethnic identity based on census bureau categories. We described population-based sampling techniques, recruitment, and follow-up strategies elsewhere (22).

We assessed participants' symptom burden at the HOPE HOME 18-month follow-up interview, using the PHQ 15. For this study, we recruited a purposive sample of eligible

participants who, at the most recent interview, met HEARTH criteria for homelessness and had either: 1) physical symptom score of  $\geq 10$  on the PHQ-15 (23), or 2) at least one bothersome physical symptom on the PHQ-15 *and* one of the following: 1) high levels of regret per the Regret Scale (24), 2) loneliness per the Three-Item Loneliness Scale (25), 3) a score of  $\geq 16$  on the Center for Epidemiologic Studies Depression Scale (CES-D) (26, 27), 4) symptoms of PTSD per the Primary Care-Post Traumatic Stress Disorder screen (PC-PTSD) (28), or 5) either hallucinations, anxiety, or violent impulses as determined by responses to questions adapted from the modified Addiction Severity Index (29).

### **Interview guide**

We developed the interview guide (Table 1) through an iterative process over four pilot interviews and made adjustments to the guide during data collection as new themes emerged. Interviewers used open-ended questions to explore aspects of symptom experience including: 1) perspectives on etiology, 2) strengths, coping and management strategies, 3) impacts on daily life and relationships, 4) exacerbating factors, 5) social support, 6) and healthcare experiences.

### **Data collection**

Between June 2016 and March 2017, study staff identified participants who met inclusion criteria. We conducted interviews in private offices at a community-based nonprofit organization serving low-income adults recording interviews and uploading recordings onto a secure server. A professional transcriptionist transcribed the recordings verbatim and de-identified participant information. The interviewers composed field memos immediately after each interview. We ceased interviewing when we reached thematic saturation.

### **Data analysis**

Based on grounded theory methodology (30, 31), A.B. and M.P. independently coded the

first five transcripts using Atlas.ti Qualitative Data Analysis Software (v 7.5.17). We discussed and wrote memos about emerging codes to clarify their scope, content, and interrelationships, developing a preliminary codebook. We revised our interview guide accordingly to address emerging questions and themes. We then conducted focused coding on each transcript and wrote analytic memos on emerging themes. To ensure validity, we discussed and resolved discrepancies in coding at various stages.

## **RESULTS**

The majority of participants (85%) were African American; 65% were men; and the median age of participants was 62 years old, with a range of 52-78 (Table 2). Interviews ranged from 30 to 80 minutes. We found four major themes relating to symptom experience: 1) relationships between symptoms, 2) symptom causes through the life course, 3) effect of symptoms on daily life, and 4) coping and alleviating factors.

### **Relationships between symptoms** (Table 3)

#### 1. Existential, psychological, and social symptoms caused as much distress as physical symptoms

Participants described how interactions with non-homeless individuals triggered feelings of shame, demoralization, and loss of dignity. One participant attributed her persistent sadness to harassment and lack of acknowledgment from new, wealthier residents of the now gentrified neighborhood in which she grew up. Another described feelings of “voicelessness” and lack of dignity—which he described as “symptoms of homelessness”—resulting from shelter staff applying rules arbitrarily:

Being here, a lot of us experience different attitudes from the staff. We feel like we’re being treated like we’re nothing because we’re homeless. Those are symptoms that a lot of us go through...we’re at the mercy of what other people decide... We have no voice. We just do what they says and that’s that...I need to have an opinion to voice, and I need that to be respected. (61-year-old man)

Needing to rely on others to meet basic needs lead to feelings of dependency and lack of dignity. Additionally, the lack of privacy, frustrations with bureaucracy, and difficulty exiting homelessness eroded participants' sense of identity and generated feelings of hopelessness, disbelief, and anxiety. Many participants described restricting activities to those necessary to meet basic needs. They described how their days felt repetitive, leading to feelings of hopelessness and futility: "Is this for real? Am I really still standing [in the shelter line] again for the last year? How did it happen? [...] I got to do this every day" (57-year-old woman). Additionally, many participants described feelings of shame from causes including estrangement from family members.

It hurts my feelings because I called [my daughter] and she didn't call me back. I felt bad because I wasn't perfect but I feel I'm a good mom. I didn't want to take her to the shelter programs with me so I let her go to her dad's house, more stable. So, that got me feeling really pretty bad that I should have done things differently. (58-year-old woman)

## 2. Interconnectedness of symptoms

Psychological and existential distress triggered and exacerbated physical symptoms; physical symptoms elicited anxiety about one's possible diagnosis or mortality. For many participants, "stress"—and resultant emotional states, such as anger or anxiety—were the mediating factor between different types of symptoms. One participant reflected on the physical symptoms elicited by thinking about the difficulty of exiting homelessness: "When I start thinking that I'm not gonna get off of this situation, my body starts to hurt, my stomach gets nauseated. It's burning like it's on fire" (54-year-old man).

### **Symptom causes through the life course** (Table 4)

#### 1. Childhood abuse lead to enduring symptomatology in older adulthood

Participants attributed ongoing symptoms to experiences of abuse during childhood.

Some described being haunted by and unable to move beyond early life childhood experiences, manifested as symptoms of depression or post-traumatic stress disorder:

I was really, seriously depressed...because I was molested. And it was like I was possessed... I had no control... . . . You know, sometimes I still cry [and] feel so lonely...[But] when I really get sad or upset is if someone tell me about their child goin' through that. (63-year-old woman)

Participants attributed to the effects of trauma their continued difficulty forming and maintaining social relationships. The ensuing social isolation often resulted in depressive symptoms and feelings of loneliness that interfered with functioning.

## 2. Manual labor was a source of physical symptoms

The majority of participants worked in low wage manual labor jobs. Some participants attributed their homelessness and physical symptoms to work-related injuries:

I first got arthritis in my 20s but I was given medication... and it went away...then about 15 years ago when I got into the warehouse industry and started working with heavier stuff, it just seemed to come back gradually. It's set in more now that I'm homeless and continuing to work and I'm doing a lot more walking. (58-year-old man)

After losing housing, some continued to work in manual labor and experienced fear and stress associated with hiding symptoms in order to avoid job loss.

## 3. Daily hassles and physical conditions of homelessness caused and exacerbated symptoms

Sleeping on uncomfortable beds, buses, or on the ground, and being exposed to the elements, led to poor sleep quality, musculoskeletal pain and headaches, and psychological and existential distress. Participants reported that environmental modifications can help improve their symptoms:

...[shelter staff] recently replaced the mats that we're sleeping on with foam cushions, and I used to have a lot of problems sleeping on those hard mats...I was noticing that I had less pain in the morning. I have a hip that's going out, its

warranty is up and it has too many miles on it...Little things like that will improve my feelings. (58-year-old man)

Participants described exacerbations of physical symptoms from traveling long distances to adhere to shelter schedules and attend appointments, and described environmental barriers to following medical regimens: “The doctor gave me some pills for it but I have no place to store them on the bus [where I sleep at night]. I was supposed to elevate [my leg] but couldn’t...And there was no place to pee” (71-year-old man).

#### 4. Aging was an explanation for symptoms

Many participants noted that premature aging was responsible for their physical symptoms and decreased functional ability:

It’s the arthritis...sometimes I feel like I’m carrying all my weight on my legs. Going up and down the bus, most of the time the bus drivers lower the platform so I can get up but - I just feel like I’ve aged so quickly in my life. (58-year-old woman)

Some participants expressed the idea that older adults may be particularly vulnerable to the stressors of homelessness and therefore more likely to experience symptoms.

#### **Effects of symptoms on daily life** (Table 4)

Many participants described the undesired effects of physical symptoms on their personality, including increases in anger, sadness, and irritability. One participant noted:

[When in pain] I don’t want to do anything. I get irritable, and...I have to watch my tongue because it’s easy for me to go off on people...I like talking to people. I’m a people person, but my physical condition and medical condition takes my personality away from me. (63-year-old man)

Participants experienced decreased energy levels and motivation and gave up activities they formerly enjoyed. They described how decreased function due to symptoms lead to their social world narrowing.

#### **Coping and alleviating factors** (Table 5)

### 1. Aging was a source of wisdom and experience

Many participants viewed their age as a source of strength, wisdom, and experience in learning to manage their symptoms, frequently describing themselves as survivors who had overcome significant hardships:

[Dealing with my symptoms] is very hard, but given what I've been through, I'll be 62 years old in three weeks...and still being here just lets me know that it can be done, given the things that I've been through...Because I've been incarcerated a lot in my life... (61-year-old man)

Some took an optimistic view of their experience of homelessness. Two participants noted, "age is nothing but a number," and described lessons they learned.

### 2. Searching for "peace of mind"

Participants used a variety of coping strategies to find "peace of mind." Several participants described how spending time with family, socializing, reading, meditating, and volunteering distracted from and alleviated symptoms. One participant who volunteered to teach bicycle maintenance commented on how this decreased his depression:

...One thing I didn't expect was when I helped people with whatever issues they were having on their bicycle, I really enjoyed that. It gave me a chance to teach someone...That's something that as soon as I signed up to do more volunteering, I felt better. It felt like a chunk of depression just fell off my shoulders at that moment. (58-year-old man)

Many participants found coping strategies that provided a sense of control to be most effective in alleviating their symptoms. Participants described their ability to stay focused and positive and "see the bigger picture" instead of blaming themselves for their symptoms or their life experiences that led to their homelessness.

### 3. Substance Use

Many participants described the role of alcohol and illicit substances as temporarily effective in quelling physical or mental distress:

[When I felt the arthritic pain in my legs] I would go buy a couple of norcos [acetaminophen/hydrocodone] from my partner. Buy a fifth of wine... Just knock myself out. Do you know what I'm saying? Just to get some sleep while my legs were hurting that bad. (71-year-old man)

However, others note that substance use may cause or exacerbate symptoms. Many participants expressed fear of becoming addicted; they were concerned about the stigma, the effects on physical health, and had concerns about “losing control” of their mind.

#### 4. Religion

Participants spoke of religion as a source of strength in facing symptoms. While some participants relied on religion to manage their symptoms, most saw them as complementary systems, with religion healing the spirit or mind, and allopathic medicine providing relief to the body. One participant spoke of the power of giving up control to God in the context of unrelenting emotional suffering: “Everything bothers me, but I have faith in God. I can't control things, he's the only one who has control and I put it in his hands” (63-year-old man).

#### 5. Companionship

Despite symptom-related changes in personality and energy level, isolation and loneliness, many participants emphasized that symptoms improved with social support from someone who understands. Many participants noted that living in shelters or in unsheltered locations brought dangers (i.e. theft) that impaired trust. Participants said that they felt listened to by behavioral and mental health providers, but were not able to voice their concerns during shorter medical appointments.

#### 6. The desire for “home”



Many participants stayed with friends or family on occasion, and described how this helped to alleviate stress and anxiety. Participants contrasted this with the lack of control in shelters and unsheltered locations:

When you are in [shelters] there are a lot of...strangers. You got to deal with hundreds of personalities. It gets to be stressful sometimes. That makes me feel really bad... I don't have control. That's why I think a lot of people stay on the street because they don't have control...I would feel better if I had my own housing, my own food. I don't want to feel like I'm some kind of a beggar...I want to have my own apartment. (57-year-old woman)

Although some participants were uncertain of their ability to exit homelessness, they hoped to have a home that would afford them privacy but allow for community. This balance between privacy and community was captured by one participant who noted he wanted "...to have a home, a place to live, and I'm going to live alone. I'm at the age now where I could be alone. I do like my friends' company, but just not every day" (65-year-old man). Furthermore, almost all suggested that their symptoms would be alleviated once they had their own homes in which they could determine their daily routines, manage their symptoms, and finally achieve "peace of mind."

## **DISCUSSION**

In a purposive sample of older homeless adults, existential, psychological and social symptoms caused distress and were interrelated. The experience of stress in one domain (e.g. social) beget stress in other domains (e.g. physical or emotional), a phenomenon known as "stress proliferation" (32). This is consistent with theories of somatization, in which psychological symptoms present as physical symptoms (33, 34). We found that participants with higher physical symptom burden had a higher prevalence of other symptom types (4).

Participants attributed symptoms to a variety of causes, such as childhood abuse, work-related injuries, and social estrangement. Common causes of homelessness among older adults

included loss of social support and loss of employment (35), stressful life events which may lead to depressive symptoms (36). Many participants experienced early life trauma including childhood abuse and incarceration (35). Participants in our study attributed PTSD-related and depressive symptoms to adverse childhood experiences (37-39).

All participants attributed symptoms to the experience of homelessness and to aging, both of which are associated with increased symptom burden and disability (3). While some causes of existential and social symptoms are unique to homelessness—such as hopelessness about exiting homelessness—others overlapped with those found in the general population. For instance, the need to rely on others to meet basic needs lead to feelings of shame, dependency, and loss of dignity, a finding consistent with work on symptom burden among older adults with multimorbidity (15).

We found that “aging” is a complex theme. As in studies of older adults in the general population with high symptom burden (15), participants reported that aging and symptom burden exacerbated feelings of dependency, social isolation, and lack of hope for the future. However, some participants attributed their strength and resilience in managing symptoms to the wisdom gained through growing older. This understanding of “aging” as both a cause of symptoms and a strength in managing them is consistent with prior studies (40).

Our participants experienced significant suffering due to stigma, including through dehumanizing interactions with non-homeless individuals. Not only is stigma towards individuals experiencing homelessness common (40), but stigmatizing attitudes by health care providers, social service providers, and shelter staff impact stigmatized individuals’ sense of identity and may negatively influence their desire to seek services (41-43).

Our study has several limitations. First, we only enrolled participants who we were able to contact and were able to come to the interview site. Thus, we may have preferentially selected participants with less complex health problems, resulting in less severe symptom burdens. Interviews focused on shared themes, and did not explore differences systematically in symptom experience based on demographic factors or duration of homelessness.

Medical and social services must adapt to meet the needs of the growing proportion of individuals experiencing homelessness who are older than age 50. Healthcare interventions attuned to both physical and non-physical forms of distress (including existential and social symptoms) have been effective in the general community in improving functional status (44), increasing quality of care, and decreasing acute care utilization (45). Given the high prevalence of existential, social, and psychological symptoms among older adults experiencing homelessness, interventions for this population could adapt the principles and services included in palliative care, to address these symptoms and provide trauma-informed care, in recognition of the role of trauma in worsening symptomatology (46, 47). Successful alleviation of symptoms may be difficult without access to housing (48). Participants emphasized the importance of housing for the management of symptoms. Housing interventions should reduce environmental stress through adaptations shown to be effective for older adults (49). To address the high prevalence of feelings of loneliness, housing interventions might provide common spaces that promote social interaction and offer community-building activities. When housing is not available, shelters can play a key role in mitigating physical symptoms by providing comfortable mattresses and secure locations to store medication, limiting noise that interferes with sleep, and reducing psychological symptoms through design that provides privacy and autonomy. Staff should recognize the need for social interaction, dignity and meaning and avoid stigmatizing

language. Creating community, providing opportunities for individuals to work or volunteer, and providing spiritual support could help alleviate symptoms. Reducing the high burden of symptoms will require coordinated interventions in healthcare, social services, and housing.

**Conflict of Interest Disclosures:** None reported.

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**Table 1: Interview Guide**

I. Opening questions	<p><u>Introduction:</u> We are studying how people feel on a day-to-day basis and, if they are not feeling well, what they do to try to feel better.</p> <p><b>1. Where you are staying right now?</b></p>
II. Eliciting symptoms	<p><b>2.</b> In this interview, I am interested in learning about the feelings that bother you the most, whether they affect your body, mind, or spirit. These could be things like [<i>choose a few of the following, can tailor based on known symptoms</i>]: having trouble breathing, stomach problems, difficulty with peeing/urinating, headaches, joint pain, feeling itchy, having trouble sleeping; feeling lonely, guilty, or regretful. <b>Do you have any things like this that bother you?</b></p> <p><b>3. Which of these feelings bothers you the most?</b> Interview should focus on 1 or 2 symptoms, or more if they are interconnected.</p>
III. Symptom narratives	<p><b>4. For the next part of the interview, we will focus on discussing</b> [symptom named by participant as worst]. <b>Tell me about a time in the last few months when it was really bothering you.</b></p> <p><b>5. What was it like when you were experiencing it, and how did you deal with it? How did it make you feel?</b> (Probe: Do you always notice right away when it is happening? If not, how do you start to notice it?)</p> <p><b>6. What do you think caused it to begin?</b> (Probe: Was there something specific that caused it to begin? Sometimes there is, sometimes there isn't).</p>
IV. Impact on daily life and activities	<p><b>7. What problems in your life have been caused by it?</b> (Probe: What changes have you had to make because of it?)</p> <p><b>8. How has it caused you to change your daily routines?</b> (Probe 1: Are there places you go more or less often because of it? Probe 2: How has it affected things like your sleep and diet? Probe 3: How has it affected your stress level/emotions?)</p> <p><b>9. How does</b> [sleeping on the street/staying in a shelter/other] <b>affect it?</b> (Probe 1: Have you ever changed where you stay for the night—either more likely to stay some place or less</p>



	likely to stay some place—because of it? Probe 2: Are there places you have stayed that have made it feel worse?)
V. Health-related behaviors	<p><b>10. What do you do to try to feel better when it is bothering you?</b> (Probe (as relevant) about: medicines, acupuncture, herbal medicines, drugs, alcohol, smoking, diet, sleep, exercise, socializing, religion).</p> <p><b>11. What do you see as your biggest strengths in dealing with it?</b></p> <p><b>12. What, if anything, do you think could make it better?</b></p> <p><b>13. Is there anything that makes you feel worse?</b> (Probe (as relevant) about: medicines, drugs, alcohol, smoking, lack of sleep, diet, religion, stress, socializing, weather).</p>
VI. Support for symptoms	<p><b>14. Have you ever told anyone about this?</b>  <b><u>Social Support Probes:</u></b> Probe 1: Many people receive support from people like pastors, ministers, imams, friends and family. Do you have anyone who supports you with this issue? Probe 2: How has this person supported you in dealing with it?</p> <p><b><u>Healthcare Experiences Probes:</u></b> Probe 1: Have you ever had the chance to talk about this with a doctor or nurse? If no...Probe 2: I would like to hear more about why you haven't discussed it with a doctor/nurse/counselor...Would you ever see a doctor/nurse/counselor for this problem? <u>If yes...</u>Probe 3: Tell me about a recent time when you spoke to your doctor/nurse about it. Probe 4: Where did you go? Probe 5: What made you go? Probe 6: How did the visit go? Probe 7: What did you tell them? Probe 8: Did they listen to you? Probe 9: What did the doctor/nurse/counselor think caused it and did you think they were right? Probe 10: What did they do for you? What did they tell you to do? Did that help? Probe 11: Were you happy with what they did?</p> <p><b>15. How, if at all, have relationships with friends, family, partners, changed because of it?</b> Probe 1: Do you see anyone in your life less often because of it? Probe 2 Do you see anyone in your life more often?</p>
VII. Closing questions	<b>16. What else do you think I should know? What do you think I should have asked but didn't?</b>

**Table 2: Study Participants**

<b>Characteristic</b>	<b>Value (n=20)</b>
Age at interview Median (range)	62 (52-78)
African American race (%)	85%
Men (%)	65%
Time since last stable housing Median (interquartile range)	5.13 (6.45)

**Table 3: Participant Quotations on Symptom Qualities**

Theme/Sub-themes	Quotations
<b>Theme 1: Symptom relationships</b>	
Existential, psychological, and social symptoms cause as much distress as physical symptoms	<p><i>“I’m getting more used to the idea that my life is a complete waste. I don’t have family. I don’t have a career. I’m not a productive human being. It’s day after day of wasting my time... I am a walking dying woman. I walk until I can’t walk anymore, and then I sit. The busses pass me by.... We are untouchables and I don’t think anybody’s going to do anything about it” (78-year-old woman)</i></p> <p><i>“[Where I sleep] affects me because my back pain is pretty real because I’m sleeping on cement, but the thing that really gets me is the future. Sometimes, there is a hopeless feeling that comes on...” (52-year-old man)</i></p> <p><i>“...My homelessness all these years is fine. I’ve adapted...The only thing really destroying me now is I want to see my mother. I think my stress and everything would be okay once I see her. I’m an older man now and I never tried to get in contact with her because I was angry. I’ve been angry for a long time now.” (54-year-old man)</i></p>
Interconnectedness of symptoms	<p><i>“My loneliness affects my mind and my body...all of [my symptoms] bother me, but number one would be the pain, and then...the pain trickles down to everything.” (63-year-old man)</i></p>

**Table 4: Participant Quotations on Causes & Effects on Daily Life**

<b>Theme 2: Causes</b>	
<p>Childhood abuse lead to enduring symptomatology in older adulthood</p>	<p><i>“You know, the whole family just hated me, but I think it was over this image that my mother had presented of me... “You’re ruined because of the molestation from your father’s boss.” ...They say a sheep or an animal raised not with other companions that are sheep, they don’t fit in... They’re not acceptable. I’m an okay person, but I’m not what anybody’s looking for as a friend, because my problems are so different.” (78-year-old woman)</i></p> <p><i>“[My father’s abuse of my mother and me], and being away from my mother for all those years is part of my mental problem. It’s part of me not being able to succeed more in life. Some people say “Oh, well. You can get over it.” A lot of people can’t get over a lot of things...Some people is not as strong as the other. I had contemplated killing myself more than once...” (54-year-old man)</i></p>
<p>Manual labor was a source of physical symptoms</p>	<p><i>“I think my pain got me lazy. I think I’m quitting on myself... Warehouse work stalled my back. I worked a lot of years in my life. I worked in a warehouse in shipping and receiving, so I’m picking up boxes, loading trucks, forklift driving. That took a toll on my back. Plus I’ve been hit by a truck on my bicycle and that messed up my leg and it never got better.” (55-year-old man)</i></p>

**Table 4: Participant Quotations on Causes & Effects on Daily Life (continued)**

<p>Daily hassles and physical conditions of homelessness caused and exacerbated symptoms</p>	<p><i>“Well [when I walk to my appointments and feel tired] I just wait on a bench until I get my energy back, but here the cops want you to move along, and I can’t move along...I guess every day that I have to walk, I’m tired. I guess that’s the main thing: that I go from bench to bench and feel tired.”</i> (61-year-old woman)</p> <p><i>“The one feeling that I have in my day-to-day life is the pain. I’ve also noticed that when I’m going through stuff I’ll notice more pain in different areas of my body... yesterday when I got my [shelter] bed [back], I felt good, I was happy, I thanked the worker and for a few moments, I felt okay. When I hit the street and was carrying all my bags, the pain returned, but that was physical pain and maybe a little bit of emotional pain...”</i> (58-year-old man)</p> <p><i>“Well, the weather, the stress and not being able to have my stuff to where I could get to it [makes me feel worse]. Having a place with a medicine cabinet or being able to constantly have access to shower, bath.... But when you’re stressed out, and don’t have no place to go, I have no house, I don’t have this, I don’t have that and along with the symptoms, it’s not good.”</i> (57-year-old woman)</p> <p><i>“I want things to start getting more like they used to be when I was housed. I’d have a social life. I like fitness and so I’m feeling like I need to try to focus and get out of this revolving shelter program. Because [it] wears down your feelings, your emotions, everything...That can wear you down and not having proper place to sleep and leave my things...”</i> (57-year-old woman)</p>
<p>Aging was an explanation for symptoms</p>	<p><i>“I’m tired, but...I’ll be 79 in a month. I think it’s just old age, but I walk two or three blocks, and sit for five to 15 minutes depending on how tired I am. This is why it takes me seven hours to get about three miles down to the clinic and then back.”</i> (78-year-old woman)</p>

**Table 4: Participant Quotations on Causes & Effects on Daily Life (continued)**

Aging was an explanation for symptoms	<i>“I think my aches and pains really have to do with my age....I’m just that old person now, not like 20 years ago when I used to look at those little people and think, “I’m never going to be like that.” I am like that now.” (71-year-old man)</i>
<b>Theme 3: Effects of symptoms on daily life</b>	
	<p><i>“I can’t be active anymore like playing sports because I used to like to go play basketball or lift weights...But I can’t do nothing anymore...because it’s too much stress and strain. It has something to do with my wind also. It affects that. If I get tired, my energy level is zero...” (63-year-old man)</i></p> <p><i>“[When I’m feeling pain, loneliness and anxiety] those are the days...where I’m like a mad man inside my room and I don’t want to communicate with anybody.” (61-year-old man)</i></p> <p><i>“I was going to tell you what I lost [because of my pain]. I lost my girlfriend. I got lazy, irritable, would cuss her out, all this kind of stuff.” (58-year-old-man)</i></p>

**Table 5: Participant Quotations on Coping and Alleviating Factors**

<b>Theme 4: Coping and alleviating factors</b>	
Aging was a source of wisdom and experience	<p><i>“The fact that I’m 60 years old and can’t do some of the things that you still like to do has been bugging me lately. If you’ve lived for a while, you can amass a bit of knowledge over the years and so I feel like I’ve come to know myself better, and that’s one of the bright sides. I also know other people a little bit better. I used to have a hard time dealing with people.”</i> (58-year-old man)</p> <p><i>“Some people just age through a normal life of whatever, jobs, stuff like that. I went through a street education growing up...As I got older, I had to learn how to put stuff aside and start doing more sociable things related to my age and surroundings...I’ll go to church or I’ll take a walk or something [so] I can get to where I’m not stressed...Because I used to get so angry....I would wind up in jail without thinking. Jail is hard, man...”</i> (63-year-old man)</p>
Searching for “peace of mind”	<p><i>“Meditate, just being by myself. Living the night, just being alone and listening to my music, that makes [my pain] feel better. I like jazz but I just listen to my music, just go away to myself. That makes me feel - I like being alone. I love being alone.”</i> (58-year-old man)</p> <p><i>“[Reading] takes my mind off of [my symptoms], and the calmer you get, the less stress you have on you, and it calms the nerves down.”</i> (63-year-old man)</p>
Substance use	<p><i>“[Marijuana] takes my mind somewhere else. I’m tweaked and I’m high. So my mind is definitely not on people, because they’re not in my way right now and they’re not being mean to me right now...I’m not tripping on them.”</i> (61-year-old woman)</p>
Religion	<p><i>“When I feel [anger over my situation] I go to the water and I pray hard. I just start praising God until I can feel the spirit come over me to comfort me...I pray until He comes and allows his spirit to wrap his arm around me; I feel a lot better...A psychiatrist can’t tell me what’s wrong with me...For someone to try to help would mean a lot. I don’t have nobody but to trust God. He’s my only psychiatrist.”</i> (54-year-old man)</p> <p><i>“[Getting better] is a matter of faith; not just pills and counseling”</i> (52-year-old man)</p> <p><i>“Some mornings...I can’t get up because I got to get up slow,</i></p>

	<p><i>and it seems like something tightens up on me. The first thing I do, I take my Doan's [magnesium salicylate] pills...They are the ones that really have me – I'm not going to say the Lord God has me going on, but He gives me the medicine for my back to keep going...I mean your medicine is God up there, whether he put it in a pill form or whatever.”(62-year-old man)</i></p>
Companionship	<p><i>“...I come [to the HOPE HOME Study] once a month and it helped me stay focused and share what I've been going through. That's why I felt my health is a little better now than it was because before that I would just constantly be in shelter after shelter after shelter.” (57-year-old woman)</i></p> <p><i>“I just use [my PCP] for referral. That's what most primary doctors do now. Your primary doctor used to do everything...Now you can talk to a doctor for only so long...[On the other hand] I see a psychiatrist. He's got a PhD...and he helps me out a lot. He donates his time. One of the nicest guys in everyone I meet...and he's concerned about his clients...Sometimes he come out to the barbecues.” (63-year-old man)</i></p> <p><i>“Being in a hospital and having all these attentive nurses and doctors come to my aid and listen to me felt really good. It was a feeling that I didn't get being at home with my family.” (59-year-old man)</i></p>
The desire for “home”	<p><i>“I have a lot of issues that I need to work on but...my main goal right now has to be housing....I can do it better if I have a place to stay and go to the doctor more and relax. When I have my own place, I'd sleep so much better.” (57-year-old woman)</i></p> <p><i>“If I have my own place, I could go home. I can relax. I don't do a lot of the things I used to do... I can go to a gym. I can go home and read. I can sit home and watch TV...I'd like to be independent, have my own place again, make my own decisions and not have to live by somebody else's decisions.” (61-year-old man)</i></p>



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