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

Adam Bazari, MS^1 , Maria Patanwala, BS^2 , Lauren M. Kaplan, $PhD^{4,5}$, Colette L. Auerswald, $MD^{1,3}$, and Margot B. Kushel, $MD^{4,5}$

¹University of California Berkeley – University of California San Francisco Joint Medical Program, Berkeley, California, USA

²University of California San Francisco School of Medicine, San Francisco, California, USA

³University of California Berkeley School of Public Health, Berkeley, California, USA

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

⁵University of California San Francisco Center for Vulnerable Populations, San Francisco, California, USA

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 using thematic analysis.

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.

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. margot.kushel@ucsf.edu, (415) 206 8655 (phone), (415) 206 5586 (administrative fax).

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Conclusion—Homelessness causes and exacerbates physical and psychological distress. Interventions should address multiple interconnected dimensions of suffering. Health systems that care for homeless patients should adapt palliative care practices using a stepwise approach. 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 in the United States 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 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 to alleviate symptoms (9).

Homelessness and older age are associated with increased symptom burden (4, 10). Homeless adults experience more pain and psychological symptoms than other patient populations approaching end of life (11). Symptom burden causes suffering, and is associated with poorer functional status, increased healthcare utilization, and death (12-14). In older adults, symptom burden is associated with 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). We used a teach-back method to obtain informed consent (20), providing 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. 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 10 on the PHQ-15 (23), or 2) 1 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 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 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 iteratively during data collection. In our initial guide, we explained our study aims, and emphasized that we were interested in discussing participants' experiences of their symptoms and interactions with the healthcare system. Based on early interviews, we expanded our interviews to focus on how participants self-managed their symptoms. 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 deidentified participant information. The interviewers composed field memos immediately after each interview. We ceased interviewing when we reached thematic saturation.

Data analysis

Using thematic analysis, A.B. and M.P. independently coded the first five transcripts using Atlas.ti Qualitative Data Analysis Software (v 7.5.17) (30). 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

We recruited 20 participants. The majority (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 as described below.

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 wealthier residents of the newly 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. Lack of privacy, frustrations with bureaucracy, and difficulty exiting homelessness eroded participants' sense of identity and generated feelings of hopelessness, disbelief, and anxiety. Participants described restricting activities to those necessary to meet basic needs. They explained that 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). 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. A 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 childhood abuse. 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 their continued difficulty forming and maintaining social relationships to their experiences of trauma. The ensuing social isolation 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 could 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—Participants emphasized 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)

Participants expressed that older adults may be particularly vulnerable to the stressors of homelessness and more likely to experience symptoms.

Effects of symptoms on daily life (Table 4)

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. 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—Participants viewed their age as a source of strength, wisdom, and experience in learning to manage their symptoms, 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 their adversities and age. 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." 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)

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—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 noted that substance use may have caused or exacerbated symptoms. Participants expressed fear of becoming addicted; they were concerned about the stigma of substance use, 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**—Participants emphasized that symptoms improved with social support from someone who understands. Participants explained how 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"**—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 explained that 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). Almost all participants 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 beget stress in other domains, a phenomenon known as "stress proliferation" (31). This is consistent with theories of somatization, in which psychological symptoms present as physical symptoms (32, 33). 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 employment (34), stressful life events which may lead to depressive symptoms (35). Participants experienced early life trauma and attributed PTSD-related and depressive symptoms to adverse childhood experiences (36-38).

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 overlaped 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).

Participants' views on "aging" were complex. 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 (39).

Our participants experienced suffering through dehumanizing interactions with non-homeless individuals. Not only is stigma towards individuals experiencing homelessness common (39), 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 (40-42).

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 have been effective in the general community in improving functional status (43), increasing quality of care, and decreasing acute care utilization (44). 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 (45, 46). Palliative care providers' expertise in managing symptoms, optimizing quality of life, delineating goals of care, and managing emotionally charged conversations, could play an important role in improving the quality of care given to older homeless adults. People experiencing homelessness receive care in resourceconstrained settings, which are less likely to have palliative care (47). Recognizing the need for palliative care, California expanded access to palliative care services to each of its 17 public hospitals; this could serve as a model to other regions (48). The Veterans Affairs (VA) system, which sees a large proportion people experiencing homelessness, offers palliative care in all settings. There is a need for expanded access to palliative care in non-VA ambulatory settings that see high numbers of homeless patients. To do so, these settings will need to create systems for assessments of symptoms and care needs, and develop pathways to triage patients who screen positive for distress, referring those at highest need to specialist palliative care providers (49, 50).

Successful alleviation of symptoms may be difficult without access to housing (51). 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 (52). 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 alleviate symptoms. Reducing the high burden of symptoms will require coordinated interventions in healthcare, social services, and housing.

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References

- Culhane DP, Metraux S, Byrne T, Stino M, Bainbridge J. The Age Structure of Contemporary Homelessness: Evidence and Implications For Public Policy. Anal Soc Issues and Public Policy. 2013; 13:228–244.
- Hahn JA, Kushel MB, Bangsberg DR, Riley E, Moss AR. BRIEF REPORT: The Aging of the Homeless Population: Fourteen-Year Trends in San Francisco. J Gen Intern Med. 2006; 21:775– 778. [PubMed: 16808781]
- 3. Brown RT, Hemati K, Riley ED, et al. Geriatric Conditions in a Population-Based Sample of Older Homeless Adults. Gerontologist. 2016; 00:1–10.
- Patanwala M, Tieu L, Ponath C, et al. Physical, Psychological, Social, and Existential Symptoms in Older Homeless-Experienced Adults: An Observational Study of the Hope Home Cohort. J Gen Intern Med. 2017
- Armstrong TS. Symptoms experience: a concept analysis. Oncol Nurs Forum, Citeseer. 2003:601–612.
- Bolano M, Ahalt C, Ritchie C, Stijacic-Cenzer I, Williams B. Detained and Distressed: Persistent Distressing Symptoms in a Population of Older Jail Inmates. J Am Geriatr Soc. 2016
- 7. Gill A, Chakraborty A, Selby D. What is symptom burden: a qualitative exploration of patient definitions. J Palliat Care. 2012; 28:83–9. [PubMed: 22860380]
- Desjarlais R. Shelter Blues: sanity and selfhood among the homeless Philadelphia: University of Pennsylvania Press; 1997
- 9. Kushel M. Older Homeless Adults: Can We Do More? J Gen Intern Med. 2012; 27:5–6. [PubMed: 22086754]
- 10. Wajnberg A, Ornstein K, Zhang M, Smith KL, Soriano T. Symptom burden in chronically ill homebound individuals. J Am Geriatr Soc. 2013; 61:126–131. [PubMed: 23205716]
- 11. Tobey M, Manasson J, Decarlo K, et al. Homeless Individuals Approaching the End of Life: Symptoms and Attitudes. J Pain Symptom Manage. 53:738–744. [PubMed: 28042064]
- Rosendal MCA, Rask MT, Moth G. Symptoms as the main problem in primary care: A cross-sectional study of frequency and characteristics. Scand J Prim Health Care. 2015; 33:91–99. [PubMed: 25961812]
- Walke LM, Byers AL, Gallo WT, Endrass J, Fried TR. The association of symptoms with health outcomes in chronically ill adults. J Pain Symptom Manage. 2007; 33:58–66. [PubMed: 17196907]
- 14. Sha MC, Callahan CM, Counsell SR, et al. Physical symptoms as a predictor of health care use and mortality among older adults. Am J Med. 2005; 118:301–6. [PubMed: 15745729]
- 15. Eckerblad J, Theander K, Ekdahl A, Jaarsma T, Hellstrom I. To adjust and endure: a qualitative study of symptom burden in older people with multimorbidity. Appl Nurs Res. 2015; 28:322–327. [PubMed: 26608433]
- Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspect Psychol Sci. 2015; 10:227–37. [PubMed: 25910392]
- Luo Y, Hawkley LC, Waite LJ, Cacioppo JT. Loneliness, health, and mortality in old age: a national longitudinal study. Soc Sci Med. 2012; 74:907–14. [PubMed: 22326307]
- 18. Perissinotto CM, Cenzer IS, Covinsky KE. Loneliness in older persons: a predictor of functional decline and death. Arch Intern Med. 2012; 172:1078–1084. [PubMed: 22710744]
- 19. Kleinman A. The illness narratives: Suffering, healing, and the human condition Basic books; 1988

 Dunn LBJD. Enhancing informed consent for research and treatment. Neuropsychopharmacology. 2001; 24:595–607. [PubMed: 11331139]

- 21. Congress US, editorDefinition of homelessness 2009Homeless Emergency Assistance and Rapid Transition to Housing Act of 2009.
- 22. Lee CT, Guzman D, Ponath C, et al. Residential patterns in older homeless adults: Results of a cluster analysis. Soc Sci Med. 2016; 153:131–140. [PubMed: 26896877]
- 23. Kroenke K, Spitzer RL, Williams JBW. The PHQ-15: Validity of a New Measure for Evaluating the Severity of Somatic Symptoms. Psychosom Med. 2002; 64:258–266. [PubMed: 11914441]
- 24. Roese NJ, Epstude KAI, Fessel F, et al. Repetitive regret, depression, and anxiety: Findings from a nationally representative survey. J Soc Clin Psychol. 2009; 28:671–688.
- Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A Short Scale for Measuring Loneliness in Large Surveys: Results From Two Population-Based Studies. Res Aging. 2004; 26:655–672.
 [PubMed: 18504506]
- 26. Y-LI W. Measurement properties of the Center for Epidemiologic studies—Depression Scale in a homeless population. Psychol Assess. 2000; 12:69–76. [PubMed: 10752365]
- 27. Haringsma REG, Beekman AT, Spinhoven P. The criterion validity of the Center for Epidemiological Studies Depression Scale (CES-D) in a sample of self-referred elders with depressive symptomatology. Int J Geriatr Psychiatry. 2004; 19:558–563. [PubMed: 15211536]
- Ouimette PWM, Prins A, Schohn M. Identifying PTSD in primary care: comparison of the Primary Care-PTSD screen (PC-PTSD) and the General Health Questionnaire-12 (GHQ). J Anxiety Disord. 2008; 22:337–343. [PubMed: 17383853]
- Cacciola JSPA, Alterman AI. Development of ASI Psychiatric Severity Cut-Off Scores To Identify Co-Occurring Psychiatric Disorders. International Journal of Mental Health and Addiction. 2008; 6:77–92.
- 30. Boyatzis R. Qualitative Information: Thematic Analysis and Code Development Thousand Oaks: CA: Sage Publications; 1998
- 31. Pearlin LI, , Bierman A. Current Issues and Future Directions in Research into the Stress Process. In: Aneshensel CS, Phelan JC, , Bierman A, editorsHandbook of the Sociology of Mental Health Dordrecht: Springer Netherlands; 2013 325340
- Ladwig K-H, M MB, Erazo N, Gündel H. Identifying somatization disorder in a population-based health examination survey: Psychosocial burden and gender differences. Psychosomatics. 2001; 42:511–518. [PubMed: 11815687]
- 33. Sullivan MK, Somatization W. The path between distress and somatic symptoms. APS Journal. 1991; 2:141–149.
- 34. Brown RT, Goodman L, Guzman D, et al. Pathways to Homelessness among Older Homeless Adults: Results from the HOPE HOME Study. PLoS One. 2016; 11:e0155065. [PubMed: 27163478]
- 35. Kendler K, Karkowski LM, Prescott CA. Causal relationship between stressful life events and onset of major depression. Am J Psychiatry. 1999; 156:837–841. [PubMed: 10360120]
- 36. Felitti VJ, Anda RF, Nordenberg D, et al. Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACE) Study. Am J Prev Med. 1998; 14:245–258. [PubMed: 9635069]
- 37. Lee CM, Mangurian C, Tieu L, et al. Childhood Adversities Associated with Poor Adult Mental Health Outcomes in Older Homeless Adults: Results From the HOPE HOME Study. Am J Geriatr Psychiatry. 2017; 25:107–117. [PubMed: 27544890]
- 38. Raposo SM, Mackenzie CS, Henriksen CA, Afifi TO. Time Does Not Heal All Wounds: Older Adults Who Experienced Childhood Adversities Have Higher Odds of Mood, Anxiety, and Personality Disorders. Am J Geriatr Psychiatry. 2014; 22:1241–1250. [PubMed: 24012227]
- 39. Grenier A, Sussman T, Barken R, Bourgeois-Guérin V, Rothwell D. 'Growing Old' in Shelters and 'On the Street': Experiences of Older Homeless People. J Gerontol Soc Work. 2016; 59:458–477. [PubMed: 27653853]
- 40. Wen CKHP, Hwang SW. Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters. J Gen Intern Med. 2007; 22:1011–1017. [PubMed: 17415619]

41. Snow DAAL. Identity work among the homeless: the verbal construction and avowal of personal identities. American Journal of Sociology. 1987; 92:1336–1371.

- 42. Rayburn RLGN. This is where you are supposed to be": how homeless individuals cope with stigma. Sociological Spectrum. 2013; 33:159–174.
- 43. Counsell SR, Callahan CM, Clark DO, et al. Geriatric care management for low-income seniors A randomized controlled trial. JAMA. 2007; 298:2623–2633. [PubMed: 18073358]
- 44. Wahl H-W, Fänge A, Oswald F, Gitlin LN, Iwarsson S. The Home Environment and Disability-Related Outcomes in Aging Individuals: What Is the Empirical Evidence? Gerontologist. 2009; 49:355–367. [PubMed: 19420315]
- 45. Katon W, Sullivan M, Walker E. Medical symptoms without identified pathology: relationship to psychiatric disorders, childhood and adult trauma, and personality traits. Ann Intern Med. 2001; 134:917–25. [PubMed: 11346329]
- 46. Hopper EKBE, Olivet J. Shelter from the storm: Trauma-informed care in homelessness services settings. Open Health Serv Policy J. 2010; 3:80–100.
- 47. Dumanovsky T, Augustin R, Rogers M, et al. The Growth of Palliative Care in U.S. Hospitals: A Status Report. J Palliat Med. 2016; 19:8–15. [PubMed: 26417923]
- 48. Parrish M. It Together: How Palliative Care Spread to All of California's Public Hospitals California Healthcare Foundation; 2013
- 49. McNeil R, Guirguis-Younger M, Dilley LB. Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals. BMC Palliat Care. 2012; 11:14. [PubMed: 22978354]
- 50. O'Connell JJ. Palliative care for homeless persons. UpToDate. 2018
- Brown RT. Health Outcomes of Obtaining Housing Among Older Homeless Adults. Am J Public Health. 2015
- 52. Szanton SL, Thorpe RJ, Boyd C, et al. Community Aging in Place, Advancing Better Living for Elders: A Bio-Behavioral-Environmental Intervention to Improve Function and Health-Related Quality of Life in Disabled Older Adults. J Am Geriatr Soc. 2011; 59:2314–2320. [PubMed: 22091738]

Table 1

Interview Guide

I. Opening questions	Introduction: 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. 1. Where you are staying right now?
II. Eliciting symptoms	 2. 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 [choose a few of the following, can tailor based on known symptoms]: having trouble breathing, stomach problems, difficulty with peeing/urinating, headaches, joint pain, feeling itchy, having trouble sleeping; feeling lonely, guilty, or regretful. Do you have any things like this that bother you? 3. Which of these feelings bothers you the most? Interview should focus on 1 or 2 symptoms, or more if they are interconnected.
III. Symptom narratives	4. For the next part of the interview, we will focus on discussing [symptom named by participant as worst]. Tell me about a time in the last few months when it was really bothering you. 5. What was it like when you were experiencing it, and how did you deal with it? How did it make you feel? (Probe: Do you always notice right away when it is happening? If not, how do you start to notice it?) 6. What do you think caused it to begin? (Probe: Was there something specific that caused it to begin? Sometimes there is, sometimes there isn't).
IV. Impact on daily life and activities	7. What problems in your life have been caused by it? (Probe: What changes have you had to make because of it?) 8. How has it caused you to change your daily routines? (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?) 9. How does [sleeping on the street/staying in a shelter/other] affect it? (Probe 1: Have you ever changed where you stay for the night—either more likely to stay some place or less 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	10. What do you do to try to feel better when it is bothering you? (Probe (as relevant) about: medicines, acupuncture, herbal medicines, drugs, alcohol, smoking, diet, sleep, exercise, socializing, religion). 11. What do you see as your biggest strengths in dealing with it? 12. What, if anything, do you think could make it better? 13. Is there anything that makes you feel worse? (Probe (as relevant) about: medicines, drugs, alcohol, smoking, lack of sleep, diet, religion, stress, socializing, weather).
VI. Support for symptoms	14. Have you ever told anyone about this? Social Support Probes: 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? Healthcare Experiences Probes: Probe 1: Have you ever had the chance to talk about this with a doctor or nurse? If noProbe 2: I would like to hear more about why you haven't discussed it with a doctor/nurse/counselorWould you ever see a doctor/nurse/counselor for this problem? If yesProbe 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? 15. How, if at all, have relationships with friends, family, partners, changed because of it? Probe 1: Do you see anyone in your life more often?
VII. Closing questions	16. What else do you think I should know? What do you think I should have asked but didn't?

Table 2

Study Participants

Characteristic	Value (n=20)	
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
Theme 1: Symptom relationships	
Existential, psychological, and social symptoms cause as much distress as physical symptoms	"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) "[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) "My homelessness all these years is fine. I've adaptedThe 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)
Interconnectedness of symptoms	"My loneliness affects my mind and my bodyall of [my symptoms] bother me, but number one would be the pain, and thenthe pain trickles down to everything." (63-year-old man)

Table 4
Participant Quotations on Causes & Effects on Daily Life

Theme 2: Causes	
Childhood abuse lead to enduring symptomatology in older adulthood	"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) "[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 thingsSome people is not as strong as the other. I had contemplated killing myself more than once" (54-year-old man)
Manual labor was a source of physical symptoms	"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)
Daily hassles and physical conditions of homelessness caused and exacerbated symptoms	"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 alongI 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." (61-year-old woman) "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" (58-year-old man) "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." (57-year-old woman) "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" (57-year-old woman)
Aging was an explanation for symptoms	"I'm tired, butI'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." (78-year-old woman)
Aging was an explanation for symptoms	"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)
Theme 3: Effects of symp	toms on daily life
	"I can't be active anymore like playing sports because I used to like to go play basketball or lift weightsBut I can't do nothing anymorebecause 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) "[When I'm feeling pain, loneliness and anxiety] those are the dayswhere I'm like a mad man inside my room and I don't want to communicate with anybody." (61-year-old man) "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)

Table 5Participant Quotations on Coping and Alleviating Factors

Theme 4: Coping and alleviating factors		
Aging was a source of wisdom and experience	"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." (58-year-old man) "Some people just age through a normal life of whatever, jobs, stuff like that. I went through a street education growing upAs I got older, I had to learn how to put stuff aside and start doing more sociable things related to my age and surroundingsI'll go to church or I'll take a walk or something [so] I can get to where I'm not stressedBecause I used to get so angry I would wind up in jail without thinking. Jail is hard, man (63-year-old man)	
Searching for "peace of mind"	"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." (58-year-old man) "[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." (63-year-old man)	
Substance use	"[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 nowI'm not tripping on them." (61-year-old woman)	
Religion	"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 meI pray until He comes and allows his spirit to wrap his arm around me; I feel a lot betterA psychiatrist can't tell me what's wrong with meFor someone to try to help would mean a lot. I don't have nobody but to trust God. He's my only psychiatrist." (54-year-old man) "[Getting better] is a matter of faith; not just pills and counseling" (52-year-old man) "Some morningsI can't get up because I got to get up slow, and it seems like something tightens up on me. The first thing I do, I take my Doan's [magnesium salicylate] pillsThey 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 goingI mean your medicine is God up there, whether he put it in a pill form or whatever." (62-year-old man)	
Companionship	"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 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 meetand he's concerned about his clientsSometimes he come out to the barbecues." (63-year-old man) "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)	
The desire for "home"	"Thave a lot of issues that I need to work on butmy 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) "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 doI can go to a gym. I can go home and read. I can sit home and watch TVI'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)	