UCSF

UC San Francisco Previously Published Works

Title

"We Really Help, Taking Care of Each Other": Older Homeless Adults as Caregivers

Permalink

https://escholarship.org/uc/item/4p61m485

Authors

Rosenwohl-Mack, Sarah Kushel, Margot Ramsey, Claire et al.

Publication Date

2019

DOI

10.1177/2333721419894765

Peer reviewed

"We Really Help, Taking Care of Each Other": Older Homeless Adults as Caregivers

Gerontology & Geriatric Medicine Volume 5: 1–8 © The Author(s) 2019 Article reuse guidelines: sagepub.com/journals-permissions DOI: 10.1177/2333721419894765 journals.sagepub.com/home/ggm



Sarah Rosenwohl-Mack, MPH¹, Margot Kushel, MD², Claire Ramsey, JD³, Margaret Handley, PhD, MPH^{2,4}, and Kelly R. Knight, PhD^{2,4}

Abstract

Objectives: Many older homeless adults maintain contact with family. We conducted a qualitative study examining the role of family caregiving for older homeless adults.

Method: We conducted semi-structured qualitative interviews with a sample of 46 homeless participants who reported spending at least one night with a housed family member in the prior 6 months.

Results: A total of 13 of 46 older adult participants provided caregiving. Themes included (a) the death of the care recipient led to the participant's homelessness; (b) feeling a duty to act as caregivers; (c) providing care in exchange for housing; (d) caregivers' ability to stay was tenuous; (e) providing care conflicted with the caregiver's needs; and (f) resentment when family was ungrateful.

Discussion: In a sample of older homeless adults in contact with family, many provided caregiving for housed family. For some, caregiving precipitated homelessness; for others, caregiving provided temporary respite from homelessness, and for others, caregiving continued during homelessness.

Keywords

caregiving, home care, disability, living arrangements, socioeconomic status

Manuscript received: September 5, 2019; final revision received: November 8, 2019; accepted: November 21, 2019.

Introduction

The homeless population is aging; approximately half of single homeless adults are aged 50 or older (Culhane et al., 2013; Hahn et al., 2006; Hurstak et al., 2017). Our research found that almost half (44%) of homeless adults aged 50 and older had their first episode of homelessness after the age of 50 (Brown et al., 2016). Despite a recovering economy and efforts to end chronic homelessness, the homeless population is growing nationally ("State of Homelessness," n.d.).

Many assume that homeless adults are estranged from family members and do not have regular contact with family; the media often portrays homeless individuals as socially isolated (Bower et al., 2017; Gelberg et al., 1990; Grenier et al., 2016), but there is little research to support this social isolation. Little is known about the events that lead to older adults being homeless or the family networks of older homeless adults.

It is common for individuals to provide unpaid caregiving services to family members who require assistance, but there is little research examining caregiving among individuals at risk for or experiencing homelessness (Roth et al., 2015). In some cases, a housed low-income individual in need of caregiving can employ a family member through the Medicaid Home and Community-Based Services (HCBS) program to provide these services, but informal unpaid caregivers provide the bulk of in-home care, delivering up to 90% of these services and providing assistance with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs) (Institute of Medicine U.S. Committee on the Future Health Care Workforce for Older Americans, 2008; Roth et al., 2015). More than 15% of adults receive some amount of unpaid caregiving (National Alliance for Caregiving [NAC] and American Association of Retired

¹UCSF School of Medicine, San Francisco, CA, USA

²Zuckerberg San Francisco General Hospital and Trauma Center, CA, USA

³Justice in Aging, Oakland, CA, USA

⁴University of California, San Francisco, USA

Corresponding Author:

Sarah Rosenwohl-Mack, 3080 Washington Street, San Francisco, CA 94115. USA.

Email: sarah.rosenwohl-mack@ucsf.edu

Persons [AARP] Public Policy Institute, 2015). Although paid caregiving provides workforce opportunities for low-income adults, unpaid informal caregiving places caregivers at risk for health and economic vulnerability (Gardiner et al., 2016). Over a third of informal caregivers have poor health or a serious health condition themselves, and 19% of informal caregivers are themselves 65 years old or older (NAC and AARP Public Policy Institute, 2015; Navaie-Waliser et al., 2002). There is prior evidence that caregiving can imperil economic security, but we know less about how caregiving can lead to homelessness and whether those who are homeless engage in caregiving (Gardiner et al., 2016; Gott & Ingleton, 2011; Sherwood et al., 2008).

The research question guiding our qualitative exploratory study is as follows:

Research Question 1: How does caregiving function in a population of older homeless adults and what is its potential role as a precipitant to, and exit from homelessness?

Design and Method

Study Rationale and Design

In this article, we report on data from a subset of interviews that discussed caregiving, drawn from a larger parent study, the Family-Assisted Housing (FAH) Study. The FAH Study is a qualitative study examining the experiences of older homeless adults who while homeless, spend some time staying with family members. The FAH Study is associated with the Health Outcomes of People Experiencing Homelessness in Older Middle Age (HOPE HOME) study, a longitudinal epidemiological study of older adults experiencing homelessness (Brown et al., 2016; Lee et al., 2016).

We recruited FAH participants (n = 46) from HOPE HOME cohort members; to be eligible for FAH, participants needed to have reported spending at least one night overnight with a housed family member (or close friend) in the prior 6 months. As part of the study, we interviewed FAH homeless participants and, separately, their family members with whom they stayed. All participants provided written informed consent.

In FAH, we sought to understand the experience of older homeless adults who stay with family members to inform services and policy decision-making for this vulnerable population. The study investigated the motivations for and consequences of short- and long-term stays with family and friends from the perspectives of older homeless adults and family members or friends who hosted them. Consistent with the social-ecological model, we explored the individual, relationship, community, and policy factors that contribute to motivations for short- and long-term stays, as well as their benefits and challenges (Stokols, 1996).

For the study reported here, the first author reviewed all available coded transcripts from the FAH Study (*n*=46)

and included the subset of participants with self-reported caregiving experiences, either formal or informal (*n*=13). We defined caregiving as providing assistance with one or more IADLs (e.g., managing money, preparing meals) or ADLs (e.g., bathing, toileting). We identified participants below with pseudonyms.

Data Collection

We conducted qualitative interviews, lasting 60–90 min. Interviews focused on participants' physical and mental health, their experience of homelessness, and their experience of short- and long-term stays with family and friends after becoming homeless. Using a semi-structured interview guide, we asked participants open-ended questions about their short- and long-term stays with family and friends. We conducted interviews in private offices at a community-based nonprofit organization serving low-income adults and/or where participants lived. All interviews were audiotaped. A professional transcriptionist transcribed the recordings verbatim and deidentified participant information. We provided a US\$25 gift card for a local retailer for participation. The Committee on Human Research of the University of California, San Francisco approved all study activities (15-16124). We ceased interviewing when we reached thematic saturation.

Data Analysis

Consistent with grounded theory methodologies, we began data analysis simultaneous to data collection (Strauss & Corbin, 1990). We engaged in three interpretative activities: (a) data summarizing and consensus data analysis discussions, (b) codebook development and coding, and (c) data synthesis and manuscript development. First, interviewers created detailed one-page summaries immediately after the completion of each qualitative interview. These summaries included the basic outline of the content participants described in the interviews as well as theoretical memoing, in which interviewers offer thematic impressions and insights (Glaser, 1998; Montgomery & Bailey, 2007). After the completion of approximately 10 qualitative interviews, the data analysis team met to discuss the transcripts and accompanying summaries. Analysis meetings included study investigators, the study project director, and study interviewers. We took detailed notes of emergent themes discussed during these meetings. After the team had discussed all summaries and transcripts, we conducted a final data analysis consensus meeting to develop the preliminary codebook.

Two researchers independently coded five interviews and then met together with a study investigator to revise code definitions, delete or collapse codes, and add new codes. Using this iterative process, we revised the codebook three additional times until no further changes were necessary and we established inter-rater reliability.

Rosenwohl-Mack et al. 3

We entered coded transcript data into the Atlas.ti Qualitative Data Analysis Software (version 7.5.17; ATLAS.ti Scientific Software Development, Berlin, Germany). The final stage of data analysis included consensus discussions with the full analytic team about the presentation of findings. We identified salient themes emergent in the consensus discussion and data coding processes, with a focus on themes' scope, inter-relationship, and relevance to current literature on older homeless adults and their familial and social networks (Sandelowski & Leeman, 2012).

Many older homeless adults in the FAH Study described caregiving experiences. We reanalyzed the FAH data, specifically looking for descriptions of these experiences. We looked closely at coded text about caregiving, comparing and contrasting descriptions of caregiving to determine the most prevalent and salient themes. To clarify the themes and the relationships between them, we completed theoretical memos (Montgomery & Bailey, 2007) about the experiences of older homeless adults acting as caregivers for housed family members.

Results

Of the 46 study participants who reported staying with housed family members for a day or longer in the prior 6 months, 87% were African American, 11% were White, and 2% were Latinx. Three quarters were men. Almost half, 45%, first became homeless at or after the age of 50. Thirteen participants (28%) described active caregiving experience; they had similar demographic characteristics to those of the rest of the study participants.

Homeless adults who engaged in caregiving reported providing care to family members and friends both before becoming homeless and while experiencing homelessness. Several of those who provided caregiving prior to becoming homeless noted that this caregiving contributed or led to their homelessness when the caregiving relationship ended. Some homeless participants reported providing caregiving services in exchange for an occasional place to stay during their homelessness episode. Two worked as paid caregivers for their family members through the In-Home Support Services (IHSS) program, an HCBS program, before they became homeless; the others provided informal care before or during homelessness. Like most caregivers, the participants reported providing assistance with ADLs (e.g., bathing, transferring) and IADLs (e.g., shopping, cleaning). They did so variably, with some providing assistance daily and others providing sporadic assistance every few months.

Below, we describe two sets of experiences. First, we describe the experiences of participants who became homeless after the end of a caregiving relationship. Second, we describe participants who provided care while experiencing homelessness.

Participants Became Homeless After the End of a Caregiving Relationship

We identified two themes for participants who became homeless after a caregiving relationship ended: (a) participants felt a duty to act as caregivers for parents at the end of their life, but doing so jeopardized their own housing and financial stability and (b) participants became homeless after the care recipient's health deterioration or death.

Duty to act as caregivers for parents at end-of-life outweighed concerns about housing instability. Looking back on when they provided caregiving, participants expressed that they had a strong sense of duty to provide caregiving, even when this precipitated homelessness. Dennis, a 62-year-old man, left his apartment to move in with his father at the end of his father's life: "I moved in with him to take care of him 24 hours a day. I would do it in a minute and I don't regret it. I just miss him real bad." He had given up his job and apartment to care for his father; after his father died, he became homeless. Anthony, a 66-year-old man, described his decision to move back home to take care of his mother: "She had health problems, so I decided to go down to [town in Texas] and help. I only meant to be there for a couple weeks but I ended up stayin' four years." To go to Texas, he left his apartment in the Bay Area for which he had received a housing choice voucher. After his mother's death, he returned to the Bay Area, but having lost his apartment and his voucher, he became homeless. Neither participant was able to stay in the care recipients' home after their deaths.

Christopher, a 68-year-old man who took care of his mother at the end of her life had been homeless sporadically over many years prior to providing caregiving. He was staying in his brother's apartment before he went to care for his mother; both he and his brother initially served as caregivers for his mother. When his brother died, Christopher cared for his mother alone. While he cared for her willingly, he was unable to take care of his own medical conditions. He recalled his physician prompting him to take better care of himself, asking, "How can you take care of your mother if you're dead?" After his mother's death, he became homeless again. His mother had paid for her rent with the assistance of a housing choice voucher, but when she died, he had to vacate the apartment and became homeless. This experience of duty and obligation is similar to the well-documented experiences of housed caregivers, many of whom view caregiving as a natural stage of life, especially when the care recipient is a parent. Caregiving can lead to economic hardship for many. In the case of the study participants, this led to their becoming homeless.

Care recipient's health deterioration or death precipitated participant's homelessness. Some participants became homeless after the care recipient they cared for required

a higher level of care than the caregiver could provide. John, a 67-year-old man, lived with his ex-wife's mother and helped take care of her:

I was staying with my kid's mother's mother, because she was elderly . . . and I was trying to help her, you know, help her out, staying around, taking her there, pushing her in the wheelchair and helping her out.

He lost his housing when she moved into a skilled nursing facility.

In some cases, caregiver participants left their residences and moved to other cities to move in with and provide caregiving for a loved one, leaving behind rentstabilized housing. With the rising cost of housing, giving up a long-held lease can precipitate homelessness (Honig & Filer, 1993). John's experience of losing housing when a family member died or moved to a higher level of care was common. After the care recipient died or moved to a higher level of care, caregivers often had no claim to the lease of the care recipient, and no home to which they could return. In other cases, the caregiver left a paying job to provide caregiving, sustaining an economic shock that depleted their savings. Even if they were paid for their caregiving, they experienced financial shock when their caregiving service ended—either through the death of the care recipient or their move to a nursing facility.

Participants Provided Care for Housed Family Members While Experiencing Homelessness

Among participants who provided caregiving during bouts of homelessness, we identified four themes: (a) during stays with family, participants provided care in exchange for housing; (b) caregivers' ability to stay with care recipients was tenuous and depended on policies and relationships; (c) providing care for others conflicted with attending to one's own needs; and (d) participants felt resentful when family members did not show appreciation.

Homeless older adults provided caregiving in exchange for temporary housing. Daniel, a 59-year-old man who had been married, a homeowner, and a business owner, became homeless after experiencing financial setbacks related to losing his job. Unable to pay his mortgage and worried about losing his home, he asked his aunt to move into his house and take over his mortgage. Ashamed about his inability to contribute financially and reluctant to live in his house without paying the mortgage, he stayed in homeless shelters and unsheltered locations. When he found a job a few years later, he moved back into his house with his aunt. However, his income did not support his ability to pay his mortgage. Because he wanted to contribute, he took care of his aunt, bringing her to appointments, cooking, cleaning, and paying for her all utilities and expenses,

including food. He characterized their relationship as reciprocal, "hand in hand."

Richard, a 57-year-old man, stayed with his sister occasionally. When he stayed, he provided caregiving to his sister, who had mental and physical health problems. While staying with her, Richard cleaned, cooked, and shopped for her; he provided emotional support by comforting her when she was distressed. He viewed this care as reciprocal: "So I'm mainly like taking care of her when I'm there. See, but we, we really help, taking care of each other."

Michael, a 55-year-old man, occasionally stayed with his mother and helped her with dishes and yardwork because she was injured and had difficulty with mobility. He noted that she sometimes tried to give him money in exchange, but he took it only if he had an immediate need. She did not have expectations for the help he would give: he said, "I do it on my own . . . No. It's just all me. When I come in there . . . I know exactly what to do. I go in there, take out the garbage and stuff like that, wash the dishes." Robert was a 60-year-old man who helped take care of his former partner's disabled mother, with whom he was staying. She did not expect him to provide care: "She just asks me. She don't expect nothin'."

Not all participants viewed caregiving as an obligation in exchange for housing. Charles, a 68-year-old man who stayed with his son one or two nights per month, had visited nearly every day since his son sustained a spinal cord injury from a gunshot injury 13 years previously. His son had a paid home health care worker who came on weekdays for 2 to 3 hr, but this was not enough time to meet his son's needs. Charles provided personal care on weekends, helping his son bathe, get dressed, and get in bed as well as helping with housework. He said, "It's just if I see somethin' that needs to be done, I just do it. It's not no return, no whatever. It's just, if I see somethin', I know he's not able to do it and I do it." This father's experience reflects a widespread observation that for care recipients with significant disabilities, IHSS allocations often fall short of need. In these cases, family members are expected to fill care gaps. When this participant stayed with his son, he stayed either in the living room or in a car in the driveway; on other nights, he slept at a homeless shelter.

Many homeless participants who took care of family members with whom they temporarily stayed viewed their caregiving as an exchange for their temporary housing. Some offered their caregiving services in lieu of rent, whereas others described the exchange as an emotional rather than a practical one.

Caregivers' ability to stay was tenuous and depended on interpersonal relationships and housing policies. Charles, the man who had visited and cared for his son nearly every day for years would have liked to live with his son on a permanent basis. But his son lived with his grandmother—Charles's ex-wife's mother—and she did not want Charles to spend more time there: "Oh, I don't think she would

Rosenwohl-Mack et al. 5

like it too much because she'd be havin' company comin' over, and—that's my main thing, yeah."

Beatrice, a 60-year-old woman lived with one of her daughters and worked as her daughter's in-home care provider. She used the money she earned to help cover the rent for her daughter's apartment. When Beatrice's daughter's health improved to the extent that she was deemed ineligible for services, Beatrice no longer received money and could thus no longer contribute to the rent. Her nephew (who contributed rent to stay with her daughter) did not like her living there without contributing to the rent: "I was not gonna come back out there because my nephew—the one that he was stayin' with her, I didn't like his attitude for me bein' there as her mom." Michael, the man who sometimes stayed with his mother after she was injured needed his father's permission before he could stay with his mother. "I just call and let her know, I say, Mom, I wanna come for a couple days, till I get enough—okay, come on, just ask your daddy, I ask him, he okays it. My daddy's strict on that." His father usually permitted him to stay, but only for a couple of days, because his father wanted to ensure Michael was self-sufficient and not dependent on his mother for assistance.

Some participants who acted as caregivers for their family members would have liked to stay with their family more frequently, but their family members either did not want them to stay or were unable to allow them to stay long term. Both policies and relationships contributed to the tenuous nature of the caregiver's ability to stay with family. In some cases, it is possible for a caregiver to move in to subsidized housing as a live-in aide, but this formal designation is not available to all caregivers, especially those who are providing temporary or sporadic care.

Providing care for others conflicted with attending to caregivers' own health needs. Some participants reported a conflict between the care they provided and their ability to meet their own needs. David, a 68-year-old man, stayed with his sister and several other people in an apartment in Oakland. When he stayed, he slept at the foot of his sister's bed. His sister was unable to get out of bed independently and had urinary and fecal incontinence. David was frustrated that she disregarded the fact that he was also sick. He had multiple chronic health problems, and said, speaking about his sister:

You don't have surgeries and stuff I ain't never had—I don't been in the hospital and almost died three times by havin' a heart attack, I had two strokes, how do you think I feel, I'm jumpin' up helpin' a person that won't help theirself.

Christopher, the 68-year-old man who cared for his mother at the end of her life, spoke about a time he neglected his own health and required hospitalization because he had been attending to his mother. He said,

"Put her priorities ahead of mine, I didn't go get my insulin because I was the only one there."

Caregiving can provide positive and negative experiences for caregivers, but informal caregivers have an increased risk of poor health (Adelman et al., 2014). For many caregivers, especially those who are older, providing care to others makes it more difficult to attend to one's own needs (Navaie-Waliser et al., 2002).

Participants resented when their caregiving was unappreciated. David, the man who slept at the foot of his sister's bed, expressed frustration at her perceived unwillingness to accept assistance to get out of bed: "She don't wanna get up, don't wanna do nothin', get up and get in your wheelchair, come outside and get some air. She don't wanna do that." He had been caring for her for a long time, and said, "She's drivin'—we all love her she's drivin' me stone up the wall. And I'm sick of it, I'm really gettin' tired." He resented always needing to look after her: "At night I be sleepin' and she wakin' me up, callin', come help me, I'm sick of this." Some participants expressed resentment and frustration when describing their current or previous roles as caregivers for their family members. Caregiving takes a physical and emotional toll: Many caregivers experience a sense of grief when becoming caregivers, as well as a lack of social support, a loss of privacy, or resentment (Lopez Hartmann et al., 2016; Pope et al., 2012; Tretteteig et al.,

Discussion and Implications

Discussion

In a sample of older homeless adults who were in contact with their family, we found that many older homeless adults provided caregiving services to housed family members. For some, caregiving precipitated their homelessness; for others, caregiving gave them a temporary respite from homelessness, and for others, caregiving continued during their ongoing homelessness. Our participants' experiences offer a counter-narrative to views of homeless people as socially isolated and disengaged in work (Bower et al., 2017; Gelberg et al., 1990; Grenier et al., 2016). Older homeless adults who provide caregiving services are both socially connected and part of an informal labor force.

We found similar interpersonal dynamics to those reported in the general population by caregivers for older relatives: homeless older adults conceptualized caregiving as an act of reciprocity for past actions, they occasionally resented it, and they recognized it as a part of their life-stage (Lopez Hartmann et al., 2016; Pope et al., 2012; Tretteteig et al., 2017). We found evidence that caregiving can both lead to homelessness among older adults and that older homeless adults used caregiving as a strategy to exit homelessness. As the crisis of homelessness among older adults continues to rise,

understanding these dynamics can present opportunities to prevent and ameliorate homelessness (Lee et al., 2016).

Even when able to work as paid professionals, caregivers receive relatively poor compensation. Both formal and informal caregivers are at economic risk, but the economic burden is worse for informal caregivers (Gardiner et al., 2016; Gott & Ingleton, 2011). For some caregivers, providing care requires them to reduce their work hours or leave jobs, with negative financial repercussions through lost wages and decreased insurance and retirement benefits (Sherwood et al., 2008). Becoming homeless as a result of caregiving is an extreme example of these repercussions. Understanding the needs of financially vulnerable informal caregivers could assist with policies that could both lessen the financial risk of caregiving, protect the housing of those who provide caregiving, and increase the supply of caregivers.

Caregiving can imperil both economic and housing security. A few participants received payments for their caregiving services through the IHSS program. However, this was the exception. Working as an IHSS caregiver did not provide consistent and sustained income. The IHSS program is consumer-driven and allows the consumer to hire and fire the provider, which means the provider works as directed by the care recipient. In addition, a consumer's allocation of IHSS services and hours is based solely on the consumer's needs. Thus, when the care recipient improved and no longer qualified for assistance, worsened and required residential care or nursing home placement, or died, caregivers lost access to their income earned through the IHSS program.

Caregivers incur a financial burden that can threaten their ability to pay for housing. In addition, caregiving can lead directly to loss of housing. In some cases, caregivers moved in with the care recipient and in so doing, left a rent-controlled or subsidized apartment. When the care recipient later required a higher level of care (such as in a nursing home) or died, the caregiver lost his or her housing if her or she could not remain in the caregiver's home.

The caregiver can also be at risk of losing housing after the care recipient dies, even if they moved into a home owned by their care recipient. In certain circumstances, the estate of the care recipient homeowner will be subject to Medicaid estate recovery. Although the state is seeking reimbursement of certain Medicaidfunded services, not the house itself, the house is an asset of the estate and can be used to pay the debt. This can result in displacement for the caregiver ("Estate Recovery and Liens," n.d.). If the care recipient was a leaseholder on a rental property, they may not be able to transfer the lease to the caregiver, placing the caregiver at risk of eviction upon the care recipient's death. Even when local regulations allow for rent holders to transfer the lease, they may not know to do so. There may be additional constraints when care recipients live in either public housing or housing paid for by housing choice

vouchers. If the caregiver was never placed on the lease, he or she would be displaced upon the death (or move to nursing facilities) of the care recipient.

Limitations and Strengths

This study has several limitations. Consistent with the design of exploratory, qualitative research studies, and grounded theory methodology, participants drove the narratives about caregiving. We did not ask about caregiving with every participant. Given the small sample size and qualitative study design, we are unable to generalize about all caregiving among older adults experiencing homelessness. Participants did report multiple and diverse contextual motivations and experiences related to caregiving, meriting further quantitative research to establish prevalence of caregiving experiences and practices. Despite these limitations, this is the first study to characterize informal caregiving relationships between homeless adults and their housed family members. This study offers a novel characterization of such relationships, using qualitative methods to explore previously unreported phenomena.

Policy Implications

To prevent homelessness caused by caregiving, there are several potential policy responses to protect the caregiver's housing and economic security. For example, renters in rent-controlled apartments who leave temporarily to provide caregiving to a loved one could be allowed to sublet their rent-controlled home, to allow them to return to the same home at the end of caregiving. In public housing or housing paid for by housing choice vouchers, where subletting is currently prohibited ("24 CFR § 982.551—Obligations of Participant," n.d.), public housing authorities could allow tenants who temporarily leave to provide caregiving to be placed at the top of the public housing waitlist or to reclaim their voucher so they can find a new unit. There could be changes to current rules regarding live-in aides. Changes could be made to the Department of Housing and Urban Development (HUD) rules regarding live-in aides to allow live-in aides to have succession rights ("Eligibility for Assistance and Occupancy", 2013); to limit the discretionary power of public housing authorities to adopt local policies regarding live-in aides ("24 CFR § 982.551—Obligations of Participant," n.d.); to eliminate the heightened standards for family members to become live-in aides ("Eligibility for Assistance and Occupancy," 2013; "24 CFR § 5.403—Definitions," n.d., p. 5); and to allow live-in aides to be converted to household members. For example, Supportive Housing for the Elderly (Housing and Urban Development funded housing for seniors) projects allow adult children to be added to the household after the initial lease is signed if that child is needed for essential care of a family member. This may provide the adult child with more Rosenwohl-Mack et al. 7

immediate housing stability; however, the children are explicitly required to relinquish any future rights to the unit in the case of their parent's death, which negatively affects their long-term housing stability. This rule while intended as a benefit to the senior may unintentionally increase housing instability and homelessness among caregivers, who may be low-income older adults. Efforts to allow the adult child to have transition time or assistance with locating other housing resources could mitigate the negative effects on the adult child.

Efforts could be made to ensure that caregivers receive payment for personal care services under the Medicaid program, where available. Paid caregivers whose care recipient no longer needed care could receive job training and support to enable them to provide those services to other clients. This would have the advantage of not only providing a possible source of income but could also alleviate shortages of paid care providers.

Nearly 9 million adults in the United States use long-term care services, including adult day service centers, nursing homes, residential care communities, hospices, and home health agencies (U.S. Department of Health and Human Services, 2014). There is a shortage of caregivers, and it is likely to worsen; by 2030, there will be an estimated national shortage of 151,000 paid direct caregivers and 3.8 million unpaid family caregivers (Osterman, 2017). As the homeless population ages, there is a greater need for paid caregivers with the cultural competence to care for this population. Providing training and job support for people who were caregivers to family or friends may provide both job opportunities for people at high risk of homelessness and fill an urgent unmet need.

Finally, providing legal services to caregivers or to those receiving the caregiving support to help them advocate for their housing rights could help alleviate evictions or displacement. This may be particularly important when the person receiving the caregiving support owns their own home and is at risk of a Medicaid estate recovery claim against the property after death. Either estate planning before death or filing an undue hardship waiver can help shield the home from a Medicaid estate claim, which could result in loss or sale of the home (Department of Health and Human Services, n.d.; "42 CFR § 433.36—Liens and Recoveries," n.d.).

The U.S. population is aging and the need for caregiving will continue to increase. Through this research, we found that some older homeless adults served as caregivers for family members in need of care. This caregiving presents both opportunities—for housing, and for reciprocal family relationships, and risks—to housing and economic stability. Ultimately, this research presents possible paths forward, both for care recipients in need of culturally competent care and for caregivers in need of employment and housing, and it calls for a more nuanced understanding of the family relationships and responsibilities that are important to older homeless adults.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

ORCID iD

Sarah Rosenwohl-Mack https://orcid.org/0000-0002-2885

References

- Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *Journal of the American Medical Association*, 311(10), 1052–1060. https://doi.org/10.1001/jama.2014.304
- Bower, M., Conroy, E., & Perz, J. (2017). Australian homeless persons' experiences of social connectedness, isolation and loneliness. *Health & Social Care in the Community*. https://doi.org/10.1111/hsc.12505
- Brown, R. T., Goodman, L., Guzman, D., Tieu, L., Ponath, C., & Kushel, M. B. (2016). Pathways to homelessness among older homeless adults: Results from the HOPE HOME Study. *PLOS ONE*, 11(5), e0155065. https://doi.org/10.1371/journal.pone.0155065
- Culhane, D. P., Metraux, S., Byrne, T., Stino, M., & Bainbridge, J. (2013). The age structure of contemporary homelessness: Evidence and implications for public policy. *Analyses of Social Issues and Public Policy*, *13*(1), 228–244. https://doi.org/10.1111/asap.12004
- Department of Health and Human Services. (n.d.). *State medicaid manual part 3: Eligibility*. https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/downloads/r75sm3.pdf
- Eligibility for Assistance and Occupancy. (2013). In *HUD* occupancy handbook 4350.3: Occupancy requirements of subsidized multifamily housing programs. (2013). https://www.hud.gov/sites/documents/43503HSGH. PDF
- Estate Recovery and Liens. (n.d.). https://www.medicaid.gov/medicaid/eligibility/estate-recovery/index.html
- 42 CFR § 433.36—Liens and recoveries. (n.d.). Retrieved June 19, 2019, from https://www.law.cornell.edu/cfr/text/42/433.36
- Gardiner, C., Brereton, L., Frey, R., Wilkinson-Meyers, L., & Gott, M. (2016). Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review. *Health and Social Care in the Community*, 24(5), 519–531. https://doi.org/10.1111/hsc.12253
- Gelberg, L., Linn, L. S., & Mayer-Oakes, S. A. (1990). Differences in health status between older and younger homeless adults. *Journal of the American Geriatrics Society*, 38(11), 1220–1229.
- Glaser, B. G. (1998). Doing grounded theory: Issues and discussions. Sociology Press.
- Gott, M., & Ingleton, C. (2011). *Living with ageing and dying: Palliative and end of life care for older people* (1st ed.). Oxford University Press.

- Grenier, A., Sussman, T., Barken, R., Bourgeois-Guérin, V., & Rothwell, D. (2016). "Growing old" in shelters and "on the street": Experiences of older homeless people. *Journal* of Gerontological Social Work, 59(6), 458–477. https:// doi.org/10.1080/01634372.2016.1235067
- Hahn, J. A., Kushel, M. B., Bangsberg, D. R., Riley, E., & Moss, A. R. (2006). Brief report: The aging of the homeless population—Fourteen-year trends in San Francisco. *Journal of General Internal Medicine*, 21(7), 775–778. https://doi.org/10.1111/j.1525-1497.2006.00493.x
- Honig, M., & Filer, R. K. (1993). Causes of intercity variation in homelessness. *The American Economic Review*, 83(1), 248–255
- Hurstak, E., Johnson, J. K., Tieu, L., Guzman, D., Ponath, C., Lee, C. T., & Kushel, M. (2017). Factors associated with cognitive impairment in a cohort of older homeless adults: Results from the HOPE HOME study. *Drug and Alcohol Dependence*, 178, 562–570. https://doi.org/10.1016/j.dru-galcdep.2017.06.002
- Institute of Medicine U.S. Committee on the Future Health Care Workforce for Older Americans. (2008). Retooling for an aging America: Building the health care workforce. National Academies Press. http://www.ncbi.nlm.nih.gov/ books/NBK215401/
- Lee, C. T., Guzman, D., Ponath, C., Tieu, L., Riley, E., & Kushel, M. (2016). Residential patterns in older homeless adults: Results of a cluster analysis. *Social Science & Medicine*, 1982(1982), 153131–153140. https://doi.org/10.1016/j.socscimed.2016.02.004
- Lopez Hartmann, M., Anthierens, S., Van Assche, E., Welvaert, J., Verhoeven, V., Wens, J., & Remmen, R. (2016). Understanding the experience of adult daughters caring for an ageing parent, a qualitative study. *Journal* of Clinical Nursing, 25(11–12), 1693–1702. https://doi. org/10.1111/jocn.13195
- Montgomery, P., & Bailey, P. H. (2007). Field notes and theoretical memos in grounded theory. Western Journal of Nursing Research, 29(1), 65–79. https://doi. org/10.1177/0193945906292557
- National Alliance for Caregiving and American Association of Retired Persons Public Policy Institute. (2015, June). *Caregiving in the U.S.* https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2002). When the caregiver

- needs care: The plight of vulnerable caregivers. *American Journal of Public Health*, 92(3), 409–413.
- Osterman, P. (2017). Who will care for us? Long-term care and the long-term workforce. Russell Sage Foundation.
- Pope, N. D., Kolomer, S., & Glass, A. P. (2012). How women in late midlife become caregivers for their aging parents. *Journal of Women & Aging*, 24(3), 242–261. https://doi. org/10.1080/08952841.2012.639676
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55(2), 309– 319. https://doi.org/10.1093/geront/gnu177
- Sandelowski, M., & Leeman, J. (2012). Writing usable qualitative health research findings. *Qualitative Health Research*, 22(10), 1404–1413. https://doi.org/10.1177/1049732312450368
- Sherwood, P. R., Donovan, H. S., Given, C. W., Lu, X., Given, B. A., Hricik, A., & Bradley, S. (2008). Predictors of employment and lost hours from work in cancer caregivers. *Psycho-Oncology*, 17(6), 598–605. https://doi. org/10.1002/pon.1287
- State of Homelessness. (n.d.). Retrieved June 25, 2019, from https://endhomelessness.org/homelessness-in-america/homelessness-statistics/state-of-homelessness-report/
- Stokols, D. (1996). Translating social ecological theory into guidelines for community health promotion. *American Journal of Health Promotion*, 10(4), 282–298. https://doi. org/10.4278/0890-1171-10.4.282
- Strauss, A. L., & Corbin, J. M. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. SAGE.
- Tretteteig, S., Vatne, S., & Rokstad, A. M. M. (2017). Meaning in family caregiving for people with dementia: A narrative study about relationships, values, and motivation, and how day care influences these factors. *Journal of Multidisciplinary Healthcare*, 10, 445–455. https://doi.org/10.2147/JMDH.S151507
- 24 CFR § 5.403—Definitions. (n.d.). Retrieved June 19, 2019, from https://www.law.cornell.edu/cfr/text/24/5.403
- 24 CFR § 982.551—Obligations of participant. (n.d.). Retrieved June 19, 2019, from https://www.law.cornell. edu/cfr/text/24/982.551
- U.S. Department of Health and Human Services. (2014). Long-term care providers and services users in the United States: Data from the national study of long-term care providers, 2013–2014 (Series 3, No. 38). https://www.cdc.gov/nchs/data/series/sr 03/sr03 038.pdf