

# Journal of Social Work in End-of-Life & Palliative Care



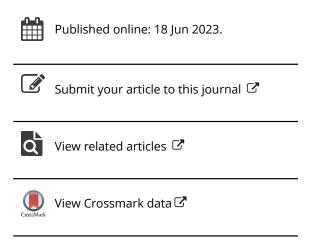
ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/wswe20

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**To cite this article:** Ian M. Johnson & Michael A. Light (2023): Pathways of Individuals Experiencing Serious Illness While Homelessness: An Exploratory 4-Point Typology from the RASCAL-UP Study, Journal of Social Work in End-of-Life & Palliative Care, DOI: 10.1080/15524256.2023.2223772

To link to this article: <a href="https://doi.org/10.1080/15524256.2023.2223772">https://doi.org/10.1080/15524256.2023.2223772</a>







# Pathways of Individuals Experiencing Serious Illness While Homelessness: An Exploratory 4-Point Typology from the RASCAL-UP Study

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The shifting age demographics of those experiencing homelessness in the United States expose shortcomings and barriers within homelessness response services and safety-net healthcare to address serious illness. The purpose of this study is to describe the common trajectories of patients concurrently experiencing homelessness and serious illness. As a part of the Research, Action, and Supportive Care at Later-life for Unhoused People (RASCAL-UP) study, the study uses patient charts (n = 75) from the only specialty palliative care program in the U.S. specifically for people experiencing homelessness. Through a thematic mixed-method analysis, a four-point typology of care pathways taken by people experiencing homelessness while seriously ill is introduced: (1) aging and dying-in-place within the housing care system; (2) frequent transitions during serious illness; (3) healthcare institutions as housing; and (4) housing as palliation. Implications of this exploratory typology include targeted, site-specific interventions for supporting goal-concordant patient care and assisting researchers and policy makers in appreciating heterogeneity in experience and need among older and chronically ill people experiencing homelessness and housing precarity.

#### **KEYWORDS**

Aging/older adults; chronic illness; community health; health disparities; homeless; medical geography; palliative care; place of care

#### Introduction

The number of unhoused people over age 50 is predicted to increase threefold by 2030 (Culhane et al., 2019). Compared to their housed peers, people in midlife and older who experience homelessness are more likely to develop serious illness (Arnold et al., 2020) and more likely to face preventable deaths from such illnesses (Funk, Greene, Dill, & Valvassori, 2022). Given the increased health and mortality risks facing unhoused people and the growing number of those over the age of 50 experiencing homelessness (Brown et al., 2017), palliative care's interaction with populations experiencing homelessness is increasingly important.

Establishing and sustaining care in an individual's preferred place is wellestablished in palliative care (Teno et al., 2018). However, systems-level inequities and complex array of medical and psychosocial barriers to care influence where care takes place for unhoused people (Davis-Berman, 2016). Palliative care research focused on unhoused people is often settingspecific, describing best practices and interventions in a specific site (Humphries & Canham, 2021). Additionally, many empirically-supported typologies of homelessness have been generated from static conceptualizations of homelessness in a moment of time (e.g., "transitional," "episodic," "chronic," "formerly") or location (e.g., "urban" vs. "rural"; "shelter" vs. "street") (McAllister, Lennon, & Kuang, 2011). While a person's historical residence is frequently the most desirable place to receive serious illness care (Munday, Dale, & Murray, 2007), the assumed absence of such a place in the lives of undomiciled older adults does not justify the lack of empirical description, theoretical attention, or development of practical responses related to overarching trajectories.

The Research, Action, and Supportive Care at Later-life for Unhoused People (RASCAL-UP) study was created in partnership with an innovative mobile palliative care team designed to care for people experiencing homelessness and serious illness. Using chart data from this interdisciplinary care team, this paper aims to identify patterns in where people experiencing serious illness while homelessness receive care. The question at the core of this study is: what are the living locations and transitions experienced by unhoused people with serious illness throughout palliative care treatment?

#### Literature review

#### Serious illness and homelessness

Encounters with both chronic homelessness and first-time housing loss are associated with the emergence of serious health conditions among older adults (Brown et al., 2017). Simultaneously, illness and disability may decrease income opportunities for households and generate exorbitant expenses in the current healthcare payment system, increasing the risk of homelessness (Almgren & Lindhorst, 2011).

Numerous factors shape healthcare and housing access for older people, including racial discrimination (Paul et al., 2020), displacement and overcrowding (Handley et al., 2022), and shifts in interpersonal and community roles (Gonyea & Melekis, 2017). When interwoven, poverty and chronic conditions create complex constraints in decision-making about housing and health (Perry et al., 2021). Older people may manage co-occurring financial demands and medical co-morbidities while lacking robust social support, health resources, or housing options (Lewinson, Thomas, &



White, 2014). Once homeless, there are few options for older adults that realistically support holistic health, reestablish desired housing, and sustain them as serious illness progresses (Canham et al., 2022).

#### Homeless palliative care

In recent years, palliative care outcomes in achieving congruence between patient's desired and actual site of care have improved (Cross, Kaufman, Quest, & Warraich, 2021; Estrada, Agarwal, & Stone, 2021), though the actual and preferred place of care during serious illness remains far less likely when older adults face displacement, housing loss, or housing instability (Chen, Chen, & Kuo, 2020). Care planning is often not feasible or acceptable given the inherent uncertainties of homelessness and the focus on daily survival (Stajduhar et al., 2019). While a gap exists in sufficiently defining specific healthcare and housing needs for older people facing homelessness and housing precarity (Finlay, 2018), documented concerns include perceived loss of choice, privacy, and familiarity associated with transfer to institutionalized care (Klop et al., 2018) and concerns of dying alone, unnoticed, or unidentified (Hubbell, 2017). Spiritual care, provider-patient trust, comfort, and autonomy have been identified as important to unhoused people during their end-of-life experiences (Webb, Mitchell, Snelling, & Nyatanga, 2020).

#### **Methods**

The RASCAL-UP study emerged from a community-university partnership with the Homeless Palliative Care (HPC) program. Its team consists of an academic researcher and practitioner-researcher from the HPC team. The study procedures were approved in July 2021 by the hospital and clinic and University of Washington institutional administration (0001348).

Since 2014, HPC has been the only known model of care in the U.S. that provides street-based specialty palliative care for people experiencing homelessness. Due to its mobile nature, HPC offers a unique ability to follow patients longitudinally across settings.

#### Sampling strategy

Eligibility for services includes homelessness as defined by Human Resource Services and Administration (HRSA) standards, which is inclusive of those whose overnight residence includes living (1) unsheltered; (2) in temporary accommodations; (3) in institutional care without plans for housing; (4) formerly homeless and in long-term supportive housing; and (5) independently housed and at risk of eviction (HRSA, 2018). Medical eligibility for service enrollment includes a diagnosis of any chronic, progressive illness with a medically documented functional decline.

Researchers engaged in a criterion-based purposive sampling strategy (Gentles, Charles, Ploeg, & McKibbon, 2015). Researcher capacity was the primary reason for opting for purposive sampling. To offset some limitations generated by this decision, researchers selected to retrieve medical records of active patient rosters from the same month (March) across a three-year period (2019–2021), helping to account for potential differences in data related to COVID-19 (Suri, 2011).

#### Collection

Retrospective chart review research design guided data collection (Vassar & Holzmann, 2013). The practitioner-researcher first de-identified electronic medical records (EMR) by removing patient medical identification and conversion of all names of people, institutions, and addresses to pseudonyms. Documentation sources included the social worker, nurse practitioner, and registered nurse, all of whom originated their roles and were actively employed by HPC at the time of data collection. Next, chronological documents were generated for the 75 sampled charts compiling all qualitative documentation from intake to discharge. The documentation in the sample spanned from December 2015 to when data collection ended in September 2021. Researchers utilized a standardized retrieval form to extract quantitative data from Word documents, such as demographics, referral information, diagnoses, a chronology of locations between referral and discharge, length of stay in each location, days of program enrollment, number of hospitalizations, and, if applicable, place of death or cause for discharge. Nominal variables were created for demographic information, referral source, and type of referring diagnoses. Numerical values for days of enrollment in the program, number of hospitalizations, length of stay in each location, length of time between referral and intake, number of comorbidities, and number of total locations. Data were electronically stored with multiple password protections.

#### Data analysis

Indicator-level classification typology model guided analysis (Bailey, 1994). Descriptive statistics were generated through SPSS (IBM Corp, 2020) for sampled patients. Researchers calculated standardized rates (z-scores) of hospitalizations and care transitions for each patient so the length of enrollment could be controlled for in examining these data points. Locations

were aggregated into five categories reflective of HRSA definition of homelessness. Patients were coded as unsheltered when they were living outdoors, in a vehicle, or part of a tent encampment. The temporary accommodations category included patients in emergency shelters, SROs, hotels/motels, transitional housing, accessory-dwelling units, or doubled-up. The supportive housing category included all housing in which residents had a lease and some form of housing assistance (e.g., rental assistance, case management, etc.). Hospitals, skilled nursing facilities, adult family homes, and jails were all retained as singular categories.

Using Dedoose Version 9.0.46 (2021), researchers began the coding process by inductively coding written text from provider documentation (Braun & Clarke, 2006). The primary investigator then developed narrative summaries (Sheard & Marsh, 2019) of each patient's journeys through care by synthesizing each patient chart and annotating documented changes in the goals of care. Then, both authors compared initial thematic codes, patterns in narrative summaries, and quantitative variables to identify emergent patterns and distinguishing characteristics. The development of themes involved a reassessment of existing literature and a memberchecking process where researchers consulted with practitioners on the HPC team. Member-checking resulted in minor linguistic clarifications, further analysis of hospice enrollment, and clarification into housing resources during terminal illness (Madill & Sullivan, 2018). Final interpretations of this exploratory typology relied on a non-algorithmic decision tree (Figure 1) to ensure mutual exclusivity of the four typologies (Pauwels, 2015), agreed upon by both authors. The root node of this decision tree was if, in the care of the HPC, the patient established a place of care identified as acceptable to them in provider documentation. Post-hoc one-way analysis of variance (ANOVA) tests were used to compare means across the four typologies.

#### Results

#### Overall sample

Table 1 depicts the sample's demographic characteristics. The racial and ethnic composition of the sample reflects that of the homeless population in the greater metropolitan area, in which Black, Latino/a/x, and American Indian/Alaska Native people are disproportionately represented in homelessness compared to the region's overall demographics (All Home, 2021). 9.3% of the sample preferred speaking a language other than English. Small subsets of the population were lesbian, gay, or bisexual (4.0%), U.S. veterans (6.7%), and undocumented residents (9.4%). The median age of patients was 63 years, with 74.66% of patients 55 years of age or older.

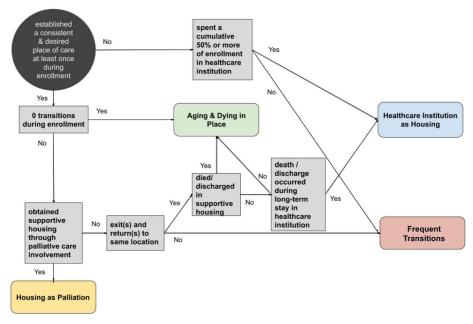


Figure 1. Typology decision tree.

**Table 1.** Sample characteristics (n = 75).

Demographic variable	Description		
Age	Median = 63		
	Mean = 60.7		
Generational cohort	2.67% Millennials (1981-1996)		
	10.67% Generation X (1965–1980)		
	69.33% Baby Boomers (1946–1964)		
	5.33% Silent Generation (1928–1945)		
Race/ethnicity	53.3% White		
,	28.0% Black/African-American		
	9.3% Latino/a/x of any race		
	8.0% American Indian/Alaska Native		
	1.3% Asian		
Gender	77.3% Men		
	21.3% Women		
	1.3% Non-binary		
Veteran status	93.3% Not Veteran		
	6.7% Veteran		
Preferred language	90.7% English		
	8.0% Spanish		
	1.3% Arabic		
Reported sexual orientation	96.0% Unrecorded		
	4.0% Lesbian, gay, or bisexual identity		
Reported citizenship	89.3% U.S. citizen		
·	9.4% Undocumented		
	1.3% Permanent resident		

Table 2 displays the primary diagnoses and comorbidities at the referral. In addition to referring diagnoses, patients had a mean of 4.85 comorbidities with a median of 5 (*SD* 1.8). All patients had a minimum of one additional diagnosis, with the number of comorbidities ranging from 2 to 9. Overall, patients were enrolled in services for a mean of 19.74 months.

	Referring diagnosis (%)	Presence overall (%)
Cancers	40.0	49.3
Chemical dependency	0.0	69.4
Endocrine conditions	0.0	22.6
Heart conditions	28.0	54.7
Gastrointestinal conditions	0.0	5.3
Infectious diseases	1.3	34.7
Lung conditions	9.3	46.7
Liver conditions	6.7	21.3
Musculoskeletal conditions	0.0	65.3
Neurological conditions	4.0	44.7
Psychiatric conditions	0.0	53.3
Renal conditions	9.3	22.6
Skin and wound care	1.3	34.7

Table 2. Referring diagnosis and comorbid diagnoses of sample by body system.

An average of 7.74 months of enrollment were spent in patients' initial site of enrollment. Patients spent an average of 16.63% of their time during HPC enrollment in the hospital—a cumulative 3.29 months. The number of location changes for each patient ranged from 0 to 88.

Among deceased patients (n = 40), 42.9% died in the hospital, 25.6% died in supportive housing, 20.0% died in a skilled nursing facility (SNF), 8.6% died doubled-up in the care of informal supports, and 2.9% died in emergency shelter settings. Among the sample, there were no recorded deaths while unsheltered. Among those who did not die while enrolled in care (n = 35), 17.3% remained active patients and 29.3% were discharged while alive for reasons including exiting geographic region (1.3%), declining further services (6.6%), stabilizing or meeting care goals (8.0%), or referral to another service that addresses patient's psychosocial, medical, and daily care needs (13.3%). Hospice referral for deceased patients (n = 40) was 21.3%, and among active patients and living discharges (n=35), hospice enrollment occurred in 4.0% of the sample.

#### Four typologies

Four typologies were identified in the locations of care experienced by patients in the sample: (1) Aging and Dying in Place; (2) Healthcare Institutions as Housing; (3) Frequent Transitions; and (4) Housing as Palliation. In the first, Aging and Dying in Place, patients experienced relative continuity of care within the housing care system and had low residential transition rates throughout their enrollment in palliative care services. Patients in this group either had no transitions in care setting or returned to their previous place of care after a stay elsewhere (e.g., returning to supportive housing after temporary admission to skilled nursing). If patients in this group died outside of their primary place of care, it was during a healthcare institution stay lasting <30 days and did not result in transfer to a new setting. The second group, Healthcare Institutions as Housing, was

characterized by at least one hospital stay of 30 days or more and/or cumulative time of 50% or more of palliative care enrollment in a hospital, skilled nursing facility, medical respite, or adult family home regardless of any previously established site of care. Patients in the third group, Frequent Transitions, did not obtain and maintain a place to actively coordinate care during the course of enrollment and spent <50% of enrollment in healthcare institutions. The fourth group, Housing as Palliation, began services without an established place of care but obtained congruence between desired and actual place of care during their palliative care enrollment.

### Aging and dying in place

Twenty patients were typologically aligned with Aging & Dying in Place. As a group, these patients spent an average of 24.02 months enrolled in services, 4.28 months longer than the mean of the overall sample. On average, patients in this group spent 17.24 months in the location they lived in when first enrolled in HPC services. They had an average of 8.32 hospitalizations during their care, which accounted for 14.30% of the cumulative time each patient was enrolled in palliative care. This was the highest mean number of hospitalizations among the four groups yet below the overall average percentage of time spent in the hospital, indicating a pattern of frequent but short hospitalizations. The average number of geographic transitions among patients during care in this group was 1.74 (Table 3).

Within this typology, eight patients had no site of care transitions during their enrollment in palliative care services. One patient had a singular residential transition between buildings within their supportive housing agency

Table 3. One-way	ANOVA of	differences i	n residential	trajectory	between typologies	
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	Mean months enrolled in HPC services	Mean months in first location	Mean hospitalizations	Mean residential transfers	Mean percent of Tx in Hosp
ANOVA F	2.07	13.63 <sup>**</sup> a,b,c	.89	7.42 <sup>**</sup> a,b,e	3.89 <sup>* d,e</sup>
All groups	19.74	7.77	7.45	3.23	16.63
Aging and dying in place	25.72	18.08	9.10	1.75	15.61
Frequent transitions	14.28	2.20	6.53	4.07	11.95
Healthcare institution as housing	16.63	7.09	5.91	2.68	25.40
Housing as palliation	21.47	1.81	8.28	4.83	10.96

<sup>\*</sup>p = <.05.

<sup>\*\*</sup>p = <.001.

<sup>&</sup>lt;sup>a</sup>Aging and dying in place and healthcare institutions as housing.

<sup>&</sup>lt;sup>b</sup>Aging and dying in place and frequent transitions.

<sup>&</sup>lt;sup>c</sup>Aging and dying in place and housing as palliation.

dHealthcare institutions as housing and frequent transitions.

eHealthcare institutions as housing and housing as palliation.

to support their care needs. Four more patients returned to their same place of residence after long-term hospitalization, skilled nursing or rehabilitation stays, or stays with loved ones. An additional seven patients spent most of their enrollment in one place but died elsewhere. These seven patients were sustained in emergency shelter or supportive housing settings for as long as possible and was then supported in end-of-life in more high acuity settings for <30 days.

Five patients in this typology exited services while alive—one patient declined further services and four were referred to other services (e.g., Program for All-Inclusive Care for the Elderly, hospice) or felt they had accomplished their care goals (e.g. disease remission).

#### Healthcare institutions as housing

Twenty-two patients met the criteria for Healthcare Institution as Housing. Overall, the group had a mean length of under the overall average (16.62 months) and an average number of hospitalizations (5.91) below the overall sample mean. However, patients in this group spent an average of 25.4% of their overall enrollment in the hospital. The average number of months spent at the patient's initial care site was 7.07, with a mean of 2.68 site transitions.

Four patients in this typology spent 100% of their palliative care enrollment in a healthcare institution (hospital, skilled nursing facility, medical respite) or between multiple healthcare institutions. Notably, one of these patients was the only patient in the full sample to be placed in an adult family home. Five patients spent between 50 and 99% of their total enrollment in palliative care within healthcare institutions; these patients had a prior history of living unsheltered and/or use in emergency shelters. Fourteen patients had at least one long-term stay in a healthcare institution and did not return to a previous location after that stay. This was most commonly the result of a transfer to skilled nursing after a hospitalization. There were no patients who followed a traditional "step-down" from the hospital to a lower-acuity setting (e.g., post-acute skilled nursing, medical respite) and then returned to a preferred previous place. Six patients within this group also shared a trajectory of unplanned exits from skilled nursing only to return to skilled nursing after either a long-term hospital stay or less medically-supportive spaces like emergency shelter, street, or county jail.

Eight patients in this typology exited services while alive, five of whom were predicted to stay in higher-acuity care through end-of-life, two who had accomplished palliative care goals, and one who declined further services when placement disrupted the care relationship.



#### Frequent transitions

The fifteen patients in the Frequent Transitions group did not obtain or maintain a place to actively coordinate care during their enrollment in palliative care and spent <50% of their total enrollment within healthcare institutions. The group's overall characteristics include a relatively short average time spent in the initial site of care during enrollment (2.09 months) and the highest rate of site of care transitions among the four groups (4.79). The group also had patterns of frequent but short hospitalizations, as indicated by a higher rate of mean hospitalizations (8.16) but a low average percent of enrollment time in the hospital (10.58%). While six of the fifteen patients in this group accessed supportive housing at some point during the trajectory of their care, they exited and did not return to the same setting. Four of six of these patients were evicted from supportive housing for behavioral reasons (e.g., assault, hoarding or related behaviors, persecutory beliefs implicating rent and rental arrears). One of the six relocated for personal safety related to historical intimate partner violence. Only one patient in this group had moved out of supportive housing prompted by physical health, and they found new supportive housing after a relatively short amount of time between the hospital and doubled-up with informal support.

Five patients in this typology exited services while alive, one of whom was lost to follow-up, two of whom met their care goals, and two of whom were referred to a different community service (e.g., traditional outpatient palliative care, forensic homeless outreach). The Frequent Transitions group less time in the hospital and were connected to palliative care services for the least amount of time of the four typologies.

#### Housing as palliation

Eighteen patients were categorized into the Housing as Palliation typology. Like the Frequent Transitions group, the average amount of time patients in this group spent in their site of care during enrollment was well below the mean (3.98 months). Their enrollment in palliative care services was 14.06 months, the lowest of the four groups. Patients in this group were referred to the team late in their illness trajectory, and some were discharged once housing access facilitated sufficient access to care and allowed for a transition into more common models of outpatient care. The mean number of residential transfers of the patients in this group was 3.93 and the percentage of enrollment spent in the hospital was 14.41%, both relatively near the overall sample mean. The patients in this group set obtaining housing as a palliative care goal, either for their own longevity and symptom management goals or for psychosocial reasons, such as meaning-



making about having a home or being able to leave housing behind for a romantic partner.

All eighteen patients spent at least 30 days outside of supportive housing at the beginning of their palliative care enrollment, obtained housing while on service and maintained supportive housing residency until death/discharge. Two patients in this typology exited services while alive, one of whom was referred to hospice and one who exited the geographic region.

#### Post-hoc testing of model

While hospitalization rate and days of enrollment were not significantly different between any of the four typologies, differences were identified in the average percent of enrollment spent in the hospital (F = 3.80, p = .01). The Healthcare Institution as Housing group spent 14.82% (SD 5.08%, p = .037) more time in the hospital during their enrollment than the Frequent Transitions typology. Overall differences were also found in the standardized site of care transitions rates (F = 7.01, p = .00). On average, the Aging and Dying in Place typology had spent 15.15 more months in their site of care when first enrolled than the Frequent Transitions typology (p = .001), and 13.26 months than the Housing as Palliation typology (p = .013). Patients in the Frequent Transitions typology had 1.24 more care transitions on average than patients in both the Aging and Dying in Place typology (p = .001) and .86 more transitions than the Healthcare Institution as Housing typology (p = .001). The Housing as Palliation typology had no significant differences from the other groups in its standardized rate of the site of care transitions. The mean difference between Frequent Transitions' rate of care transitions and other groups was not significant. No other differences between groups were statistically significant. Though crosstabulations showed lower rates of hospice enrollment in the Frequent Transitions group, hospice enrollment rates and reasons for the discharge were not found to be significantly different between groups. Inferential tests align with the decisional processes of the model. Aging and Dying in Place was differentiated through low care transition rate and a sustained presence in one primary location. Healthcare Institution as Housing was set apart from the Frequent Transitions group due to the percentage of palliative care enrollment spent in hospital settings and therefore, less general movement through other locations. The Frequent Transitions group had more care transitions than the two groups conceptualized as more static and was not significantly different in care transition rate from Housing as Palliation, who were patients who may have had more care transitions during their enrollment before obtaining housing. The Housing as Palliation group was significantly different from the Aging



and Dying in Place group in the length of time spent in the location where they were enrolled in services because these were patients whose housing needs were addressed later in their care.

#### **Discussion**

The four exploratory typological patterns in this analysis provide an understanding of key variables in the trajectories of palliative care patients experiencing homelessness. The Aging and Dying in Place typology identifies a subgroup of palliative care patients able to achieve continuity of care within the housing care continuum. Patients in the Aging and Dying in Place group had the longest periods of enrollment in care, fewer care transitions, and death in a familiar non-institutional place. However, it is important to note that those who remained in place through their illness trajectory did not have significant differences in hospitalization rates compared to other groups.

Those over 65 years of age have been shown to have longer stays in shelters (Hao, Garfield, & Purao, 2021) but with complex socioemotional experiences in these settings juxtaposed with hope and grief (Burns, Sussman, & Bourgeois-Guerin, 2018) and in which feeling "in-place" vacillates (Burns, 2016). Patients who exit emergency shelters for supportive or independent housing may experience reduced on-site support (Cusack, Montgomery, Blonigen, Gabrielian, & Marsh, 2016), increased challenges and burdens in living alone, and cultural shifts in behavioral expectations of residents (Taylor & Johnson, 2021). Permanent housing may be optimal for many older people with histories of homelessness, even though siloed care and a lack of cross-specialty expertise create risk factors for tenants aging in supportive housing (Shaley, Fields, & Shapiro, 2020). Healthcare systems may be uniquely suited to develop shelter and housing models for those experiencing serious illness. Hospital and healthcare systems are increasingly engaging in housing interventions to address social determinants of health (Horwitz, Chang, Arcilla, & Knickman, 2020). Like palliative care, harm reduction models like Housing First center on self-determination and quality of life in balancing risk with patient choice (McNeil, Guirguis-Younger, & Dilley, 2012). Such models have proven cost-effective (Bamberger & Dobbins, 2015), acceptable to tenants, and generative of positive health outcomes (Palimaru, McBain, McDonald, Batra, & Hunter, 2021). Housing does not negate the need for hospitalization for those with serious illnesses but offers an opportunity to reduce the amount of time spent in hospitals. Given the hospitalization rate of this typology, as well as the observed lack of returns to supportive housing from post-acute settings, collaborative care models between the



housing care continuum and palliative care may support appropriate hospitalization and patient-directed discharge planning.

In the last two decades, the overall percentage of deaths that occur in hospital and nursing facilities have declined (Cross et al., 2021). Through the identification of the Healthcare Institutions as Housing typology, it can be speculated that interventions aimed at facilitating care and site of endof-life elsewhere may not reach homeless or housing-precarious patients. Among unhoused people with serious illness, risk factors for hospital death included being younger in age, having more comorbidities, and receiving less outpatient care (Hicks et al., 2018). This study provides further indication that discharging unhoused patients from the hospital is often a matter of medically stabilizing someone enough to return to an inadequate place of care within the homeless response system or making a case to place someone in a highly-restrictive institutional care environment when it may be less desired and less necessary than community-based options.

While adult family homes may offer a less institutionalized place to receive high-acuity care, barriers to end-of-life care include alignment and fit with patient values and reliance on communication with resident's informal caregivers (Washington, Demiris, Oliver, Purnell, & Tatum, 2018). Those who are homeless at end-of-life face stigma may have end-of-life wishes outside of dominant cultural values, and may not have available supports to sustain care and residence in adult family homes or skilled nursing. Factors, such as serious mental illness, historic or active alcohol and drug use, and histories of criminal-legal involvement can prevent placement (Hernandez & Newcomer, 2007). Kushel (2018) provides initial evidence that patients experiencing homelessness have a much higher likelihood of being discharged to a nursing home than to lower levels of care and have longer stays in rehabilitation and skilled nursing despite loweracuity needs. This study's observation of movement in and out of different skilled nursing facilities due to unplanned exits, such as eviction or patient departure against medical advice suggests that the mismatch in fit in subacute care settings extends beyond admissions and discharge processes.

The Frequent Transitions typology illuminates a pattern of regular movement throughout treatment between actual and desired places of care for a subgroup of the sample who moved between sanctioned and unsanctioned encampments, tiny homes, emergency shelters, informal care settings, jails, sobering centers, and residential substance abuse treatment. Those in this typology spent significant time unsheltered and had more care transitions during enrollment. Municipal strategies designed to confine and expel people experiencing homelessness (Kaufman, 2022) may narrow opportunities for establishing stability in a place that facilitates patient's health goals.

Shelter systems, even those with embedded health supports and low-barrier policies, continue to face accessibility issues and elevated social and environmental risks for older and seriously-ill users. The response to decongregate emergency shelters during COVID-19 pandemic highlighted potential benefits to health and healthcare access (Johnson, Light, Perry, Moore, & Lewinson, 2023) and may be particularly suitable for patients in this typology who may have less familiarity with the experience of homelessness or housing loss (Humphries & Canham, 2021), and/or histories of institutional trauma or aversion to formal services (Scutella, Wood, & Johnson, 2021).

Within this typology, patients doubled-up frequently. Doubling up may demonstrate resourcefulness in meeting personal care goals and practical care needs within the context of limiting resources and systems and may be of increasing value to patients and informal care partners as diseases progress. Informal caregivers in the United States are under-supported in financial incentives (Ornstein, Kelley, Bollens-Lund, & Wolff, 2017) and in supplemental community-based formal caregiving services Ankuda, Aldridge, Husain, & Ornstein, 2020). Financial recognition for caregivers may also affect housing and care options for older people experiencing homelessness, particularly among those who may be averse to medical institutions or housing/shelter care, particularly considering the material and sociopolitical burdens on those networks (Cummings, Lei, Hochberg, Hones, & Brown, 2022). Historic alienation from family (Padgett et al., 2012) may alter both client goals of care as well as the capacities and motivations for families to reunify through caregiving or cohabitation.

In the Housing as Palliation typology, patients spent at least the first month of enrollment unsheltered, in emergency shelters, doubled-up, in medical respite, or undergoing eviction procedures. These patients all secured apartments in supportive or low-income senior housing during their enrollment in palliative care. This group spent the least amount of time in the hospital and largely died in a home setting. Those who did die in the hospital had short final stays. This final typology provided insight into the potential housing benefits of specialized healthcare. Mobile health interventions are positively associated with exits from homelessness and are generally found to be acceptable by homeless populations (Moczygemba et al., 2021). There is an established link between medical treatment adherence and housing retention (Collins et al., 2013). There is a possibility that patients in this group became eligible for housing assistance as their symptoms worsened or functionality decreased—the county where the study occurred has a waitlist for a terminally-ill housing voucher system, and vulnerability scores on housing triage and coordinated entry tools may

increase when people experience a functional decline. However, there are very few additional housing resources for those who are seriously ill (Shoenfarber & Adams, 2022). As the illness progresses, people may also begin having more interactions with formal support services or may have shifts in priorities and goals that can impact how people engage with mechanisms for housing support. It is suggested through this study that the sooner seriously-ill patients can receive housing post-diagnosis and prognosis, the more positive treatment outcomes may be related to goal concordance, quality of life, and comfort measures.

There are several limitations of note. Due to the sample size, all statistical procedures were exploratory and presented to guide future research that tests its generalizability. The same researchers who developed the sampling strategy also interpreted the findings, which may create sampling bias (Robinson, 2014). The generalizability of this study may also be limited by variations in municipal and state funding, legislation, and response strategies, as well as local histories and geographies. Testing this typology with larger samples or across sites and regions may help verify or further clarify themes and patterns. Future directions may include multi-site comparisons utilizing Homeless Management Information Systems (HMIS), hospital, and municipal public health data.

The sample size limited this study's ability to examine the unique outcomes among groups overrepresented in homeless populations, such as veterans, people of color, and LGBTQ people. Theoretical guidance and empirical literature suggest there may be associations between some variables whose null hypotheses could not be rejected at this time due to sample size. For example, Veteran's Association has different policies that may affect receipt and location of care. Purposive theoretical sampling in this research may enhance the understanding of how demographic and health variables could impact trajectories.

While the HPC was chosen as a research site due to its novel ability to observe longitudinal location changes among homeless palliative care patients, patient pathways may be altered by involvement in HPC's specific model of care. Translational research of the HPC model of care is needed to understand the ways in which the HPC patient experience differs from people experiencing homelessness both eligible but not enrolled in palliative care, as well as receiving palliative care through traditional outpatient delivery models.

#### **Conclusion**

Being and becoming ill while without stable housing continues to be an experience for many. While we work to dismantle the structural forces that drive housing precarity and health disparities among older adults, we must intervene in the present moment. Homeless services and their research partners have begun to identify and address the needs of aging populations within the housing care continuum but without careful consideration of the locations and movements of this population. Through this study, we identified four pathways in care for people facing serious illness while unhoused. Each of these four exploratory typologies identifies unique needs and lay the groundwork for translational research targeting the creation and adaptation of setting-specific interventions. Such interventions include training in supportive housing, the redesign of models of care intended to be strictly rehabilitative, and robust mobile community-based services specifically intended for those receiving palliative and end-of-life care. By demystifying the pathways of care during homelessness, goal-concordant patient care becomes more possible, and researchers, policy makers, and practitioners are better equipped for designing, funding, and implementing programs that address a range of needs.

#### **Funding**

The author(s) reported there is no funding associated with the work featured in this article.

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#### Data availability statement

Data from this study is not publicly available. Our study materials and analytic methods are available for replication with other datasets by contacting the corresponding author. This study was not pre-registered.

#### References

All Home (2021). Seattle/King County point-in-time count of individuals experiencing homelessness. King County Regional Homeless Authority. Retrieved December 3, 2021, from https://kcrha.org/king-county-point-in-time-count/

Almgren, G., & Lindhorst, T. (2011). The safety-net health care system: Healthcare at the margins. New York: Springer Publishing Company.

Arnold, E. M., Strenth, C. R., Hedrick, L. P., Paterson, R. C., Curiel, J., Joseph, A. E., ... Kimball, J. N. (2020). Medical comorbidities and medication Use among homeless adults seeking mental health treatment. Community Mental Health Journal, 56(5), 885-893. doi: 10.1007/s10597-020-00552-4

Bailey, K. (1994). An introduction to classification techniques. In Typologies and taxonomies. Los Angeles, CA: SAGE Publications.



- Bamberger, J. D., & Dobbins, S. K. (2015). A research note: Long-term cost effectiveness of placing homeless seniors in permanent supportive housing. Cityscape, 17(2), 269-278. Retrieved from https://www.jstor.org/stable/26326949
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa
- Brown, R. T., Hemati, K., Riley, E. D., Lee, C. T., Ponath, C., Tieu, L., ... Kushel, M. B. (2017). Geriatric conditions in a population-based sample of older homeless adults. The Gerontologist, 57(4), 757-766. doi:10.1093/geront/gnw011
- Burns, V. F. (2016). Oscillating in and out of place: Experiences of older adults residing in homeless shelters in Montreal, Quebec. Journal of Aging Studies, 39, 11-20. doi:10.1016/j. jaging.2016.08.001
- Burns, V. F., Sussman, T., & Bourgeois-Guerin, V. (2018). Later-life homelessness as disen-Canadian Journal on Aging, 37(2), franchised grief. 171-184. S0714980818000090
- Canham, S. L., Walsh, C. A., Sussman, T., Humphries, J., Nixon, L., & Burns, V. F. (2022). Identifying shelter and housing models for older people experiencing homelessness. Journal of Aging and Environment, 36(2), 204-225. doi:10.1080/26892618.2021.1955806
- Chen, A. Y., Chen, B., & Kuo, C. C. (2020). Better continuity of care improves the quality of end-of-life care among elderly patients with end-stage renal disease. Scientific Reports, 10(1), 1-10. doi:10.1038/s41598-020-76707-w
- Collins, S. E., Malone, D. K., & Clifasefi, S. L. (2013). Housing retention in single-site housing first for chronically homeless individuals with severe alcohol problems. American Journal of Public Health, 103(Suppl 2), S269-S274. https://doi.org/10.2105/AJPH.2013. 301312
- Cross, S. H., Kaufman, B. G., Quest, T. E., & Warraich, H. J. (2021). National trends in hospice facility deaths in the United States, 2003-2017. Journal of Pain and Symptom Management, 61(2), 350-357. doi:10.1016/j.jpainsymman.2020.08.026
- Culhane, D., Doran, K., Schretzman, M., Johns, E., Treglia, D., Byrne, T., ... Kuhn, R. (2019). The emerging crisis of aged homelessness in the U.S.: Could cost avoidance in health care fund housing solutions? International Journal of Population Data Science, 4(3), 1-21. doi:10.23889/ijpds.v4i3.1185
- Cummings, C., Lei, Q., Hochberg, L., Hones, V., & Brown, M. (2022). Social support and networks among people experiencing chronic homelessness: A systematic review. American Journal of Orthopsychiatry, 92(3), 349-363. doi:10.1037/ort0000616
- Cusack, M., Montgomery, A. E., Blonigen, D., Gabrielian, S., & Marsh, L. (2016). Veteran returns to homelessness following exits from permanent supportive housing: Health and supportive services use proximal to exit. Families in Society: The Journal of Contemporary Social Services, 97(3), 221-229. doi:10.1606/1044-3894.2016.97.23
- Davis-Berman, J. (2016). Serious illness and end-of-life care in the homeless: Examining a service system and a call for action for social work. Social Work & Society, 14(1), 1613-8953.
- Dedoose Version 9.0.46 (2021). Web application for managing, analyzing, and presenting qualitative and mixed method research data. Los Angeles, CA: Sociocultural Research Consultants, LLC. Retrieved from www.dedoose.com
- Estrada, L. V., Agarwal, M., & Stone, P. W. (2021). Racial/ethnic disparities in nursing home end-of-life care: A systematic review. Journal of the American Medical Directors Association, 22(2), 279-290.e1. doi:10.1016/j.jamda.2020.12.005



- Finlay, J. M. (2018). Cities of (in)difference: A mixed-methods analysis of place and wellbeing in later life (Doctoral dissertation). University of Michigan. ProQuest Dissertation and Theses Global.
- Funk, A. M., Greene, R. N., Dill, K., & Valvassori, P. (2022). The impact of homelessness on mortality of individuals living in the United States: A systematic review of the literature. Journal of Health Care for the Poor and Underserved, 33(1), 457-477. doi:10.1353/ hpu.2022.0035
- Gentles, S. J., Charles, C., Ploeg, J., & McKibbon, K. (2015). Sampling in qualitative research: Insights from an overview of the methods literature. The Qualitative Report, 20(11), 1772-1789. doi:10.46743/2160-3715/2015.2373
- Gonyea, J. G., & Melekis, K. (2017). Older homeless women's identity negotiation: Agency, resistance, and the construction of a valued self. The Sociological Review, 65(1), 67-82. doi:10.1111/1467-954X.12369
- Handley, M. A., Kushel, M., Weeks, J., Olsen, P., Castillo, J., & Knight, K. R. (2022). Ground-truthing the experiences of homeless older adults' recent stays with family and friends: A case study of participatory data analysis. Journal of Health Care for the Poor and Underserved, 33(1), 268-285. doi:10.1353/hpu.2022.0020
- Hao, H., Garfield, M., & Purao, S. (2021). The determinants and length of homeless shelter stays: Evidence-based regression analysis. International Journal of Public Health, 66, 1604273. doi:10.3389/ijph.2021.1604273
- Hernandez, M., & Newcomer, R. (2007). Assisted living and special populations: What do we know about differences in use and potential access barriers? The Gerontologist, 47(suppl 1), 110–117. doi:10.1093/geront/47.Supplement 1.110
- Hicks, K., Downey, L., Engelberg, R. A., Fausto, J. A., Starks, H., Dunlap, B., ... Randall, J. (2018). Predictors of death in the hospital for patients with chronic serious illness. Journal of Palliative Medicine, 21(3), 307-314. doi:10.1089/jpm.2017.0127
- Horwitz, L. I., Chang, C., Arcilla, H. N., & Knickman, J. R. (2020). Quantifying health systems' investment in social determinants of health, by sector, 2017. Health Affairs, 39(2), 192-198. doi:10.1377/hlthaff.2019.01246
- Hubbell, S. A. (2017). Advance care planning with individuals experiencing homelessness: Literature review and recommendations for public health practice. Public Health Nursing, 34(5), 472-478. doi:10.1111/phn.12333
- Human Resources & Services Administration (2018). Bureau of Primary Health Care program terms and definitions. Retrieved from https://www.hrsa.gov/sites/default/files/ grants/apply/assistance/Buckets/definitions.pdf
- Humphries, J., & Canham, S. L. (2021). Conceptualizing the shelter and housing needs and solutions of homeless older adults. Housing Studies, 36(2), 157-179. doi:10.1080/ 02673037.2019.1687854
- IBM Corp (2020). IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY: IBM Corp. Johnson, I. M., Light, M. A., Perry, T. E., Moore, M., & Lewinson, T. (2023). Understanding the ephemeral moment of COVID avoidance hotels: Lessons learned from acknowledging housing as central to dignified later life. Journal of Gerontological Social Work, 66(1), 3-28. doi:10.1080/01634372.2022.2087129
- Kaufman, D. (2022). Expulsion: A type of forced mobility experienced by homeless people in Canada. Urban Geography, 43(3), 321-343. doi:10.1080/02723638.2020.1853919
- Klop, H. T., De Veer, A. J., Van Dongen, S. I., Francke, A. L., Rietjens, J. A., & Onwuteaka-Philipsen, B. D. (2018). Palliative care for homeless people: A systematic review of the concerns, care needs and preferences, and the barriers and facilitators for



- providing palliative care. BMC Palliative Care, 17(1), 1-16. doi:10.1016/j.jpainsymman. 2018.05.026
- Kumar, V., Ankuda, C. K., Aldridge, M. D., Husain, M., & Ornstein, K. A. (2020). Family caregiving at the end of life and hospice use: A national study of Medicare beneficiaries. Journal of the American Geriatrics Society, 68(10), 2288-2296. doi:10.1111/jgs.16648
- Kushel, M. (2018). Homelessness: A potent risk factor for readmission. Medical Care, 56(6), 457-459. doi:10.1097/mlr.0000000000000920
- Lewinson, T., Thomas, M. L., & White, S. (2014). Traumatic transitions: Homeless women's narratives of abuse, loss, and fear. Affilia, 29(2), 192-205. doi:10.1177/0886109913516449
- Madill, A., & Sullivan, P. (2018). Mirrors, portraits, and member checking: Managing difficult moments of knowledge exchange in the social sciences. Qualitative Psychology, 5(3), 321-339. doi:10.1037/qup0000089
- McAllister, W., Lennon, M. C., & Kuang, L. (2011). Rethinking research on forming typologies of homelessness. American Journal of Public Health, 101(4), 596-601. doi:10.2105/ AJPH.2010.300074
- McNeil, R., Guirguis-Younger, M., & Dilley, L. B. (2012). 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 Palliative Care, 11(1), 1-8. doi: 10.1186/1472-684X-11-14
- Moczygemba, L. R., Thurman, W., Tormey, K., Hudzik, A., Welton-Arndt, L., & Kim, E. (2021). GPS mobile health intervention among people experiencing homelessness: Prepost study. JMIR mHealth and uHealth, 9(11), e25553. doi:10.2196/25553
- Munday, D., Dale, J., & Murray, S. (2007). Choice and place of death: Individual preferences, uncertainty, and the availability of care. Journal of the Royal Society of Medicine, 100(5), 211-215. doi:10.1177/014107680710000509
- Ornstein, K. A., Kelley, A. S., Bollens-Lund, E., & Wolff, J. L. (2017). A national profile of end-of-life caregiving in the United States. Health Affairs, 36(7), 1184-1192. doi:10.1377/ hlthaff.2017.0134
- Padgett, D. K., Smith, B. T., Henwood, B. F., & Tiderington, E. (2012). Life course adversity in the lives of formerly homeless persons with serious mental illness: context and meaning. The American Journal of Orthopsychiatry, 82(3), 421-430. https://doi.org/10.1111/j. 1939-0025.2012.01159.x
- Palimaru, A. I., McBain, R. K., McDonald, K., Batra, P., & Hunter, S. B. (2021). Perceived care coordination among permanent supportive housing participants: Evidence from a managed care plan in the United States. Health & Social Care in the Community, 29(6), 259-268. doi:10.1111/hsc.13348
- Paul, D. W. Jr., Knight, K. R., Olsen, P., Weeks, J., Yen, I. H., & Kushel, M. B. (2020). Racial discrimination in the life course of older adults experiencing homelessness: Results from the HOPE HOME study. Journal of Social Distress and the Homeless, 29(2), 184-193. doi:10.1080/10530789.2019.1702248
- Pauwels, L. (2015). Reframing visual social science: Towards a more visual sociology and anthropology. Cambridge: Cambridge University Press.
- Perry, T., Berglund, L., Mah, J., Sanford, C., Schaeffer, P., & Villeneuve, E. W. (2021). Advocating for the preservation of senior housing: A coalition at work amid gentrification in Detroit, Michigan. Housing Policy Debate, 31(2), 254-273. doi:10.1080/10511482. 2020.1806899
- Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. Qualitative Research in Psychology, 11(1), 25-41. doi:10.1080/14780887. 2013.801543



- Scutella, R., Wood, G., & Johnson, G. (2021). Sitting in the waiting room: Do people experiencing homelessness underutilize health services? Housing and Society, 48(3), 261-291. doi:10.1080/08882746.2020.1835116
- Shalev, D., Fields, L., & Shapiro, P. A. (2020). End-of-life care with individuals with serious mental illness. Psychosomatics, 61(5), 428-435. doi:10.1016/j.psym.2020.06.003
- Sheard, L., & Marsh, C. (2019). How to analyse longitudinal data from multiple sources in qualitative health research: the pen portrait analytic technique. BMC Medical Research Methodology, 19(1), 1–10. https://doi.org/10.1186/s12874-019-0810-0
- Shoenfarber, A., & Adams, P. (2022). A house is not a home: Palliative care with people experiencing homelessness. In T. Altilio, S. Otis-Green, & J. G. Cagle (Eds.), The Oxford textbook of palliative social work. 2nd ed. Oxford: Oxford University Press. doi:10.1093/ med/9780197537855.001.0001
- Stajduhar, K. I., Mollison, A., Giesbrecht, M., McNeil, R., Pauly, B., Reimer-Kirkham, S., ... Rounds, K. (2019). "Just too busy living in the moment and surviving": Barriers to accessing health care for structurally vulnerable populations at end-of-life. BMC Palliative Care, 18(1), 11-11. doi:10.1186/s12904-019-0396-7
- Suri, H. (2011). Purposeful sampling in qualitative research synthesis. Qualitative Research Journal, 11(2), 63-75. doi:10.3316/QRJ1102063
- Taylor, S., & Johnson, G. (2021). Examining tenancy duration and exit patterns in a singlesite, mixed-tenure Permanent Supportive Housing setting. Housing and Society, 48, 1-24. doi:10.1080/08882746.2021.2009734
- Teno, J. M., Gozalo, P., Trivedi, A. N., Bunker, J., Lima, J., Ogarek, J., & Mor, V. (2018). Site of death, place of care, and health care transitions among U.S. Medicare beneficiaries, 2000–2015. JAMA, 320(3), 264–271. doi:10.1001/jama.2018.8981
- Vassar, M., & Holzmann, M. (2013). The retrospective chart review: Important methodological considerations. Journal of Educational Evaluation for Health Professions, 10, 12. doi:10.3352/jeehp.2013.10.12
- Washington, K. T., Demiris, G., Oliver, D. P., Purnell, G., & Tatum, P. (2018). Quality hospice care in adult family homes: Barriers and facilitators. Journal of the American Medical Directors Association, 19(2), 136-140. doi:10.1016/j.jamda.2017.08.012
- Webb, W. A., Mitchell, T., Snelling, P., & Nyatanga, B. (2020). Life's hard and then you die: The end-of-life priorities of people experiencing homelessness in the UK. International Journal of Palliative Nursing, 26(3), 120–132. doi:10.12968/ijpn.2020.26.3.120