

An Exploratory Study of End-of-Life Planning Among Unsheltered and Unhoused Individuals

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Introduction

End-of-life (EoL) planning in homeless individuals remains critically understudied. There is a profound gap in understanding how the absence of a stable shelter shapes their ability and perspectives regarding EoL planning. Existing literature on this population most often centers on ‘solving’ homelessness or examining its causes, often neglecting the perspectives and needs of the homeless population (Hubbell, 2017).

This research began after learning from accounts by unhoused individuals who professed an intense desire to retreat to remote areas to die alone (Bruder, 2018). These accounts stirred a question: *What is end-of-life planning like when you don't have access to a permanent structure, but you do have access to a vehicle?* Building on these narratives, the study focuses on understanding how the experience of homelessness shapes EoL planning and the experiences of those dying without stable housing or resources.

Background

What is EoL Planning?

Many formal studies related to homeless healthcare emphasise advance care planning (ACP). ACP constitutes a process in which individuals plan for the future (American Psychological Association, 2010). ACP often includes legal documentation, agreements with family and friends, and the designation of a proxy. Studies have found that the most likely to participate in ACP are the elderly and those with chronic illnesses (American Psychological Association, 2010). In contrast, End-of-Life (EoL) planning can be understood as having two specific spheres relating solely to one's own expiration:

1. Legal: This often includes, but is not limited to, designation of a next of kin and creation of a will (Brock, 2024).

2. Medical: This often includes, but is not limited to, creation of a medical plan and plans for processing of one's body (Saraiya et al., 2008).

In this sense, EoL plans can be understood as a specific aspect within ACPs that concerns preferences and decisions about the process of dying and post-death wishes. In addition to the two main spheres, EoL plans may include informal or spiritual elements along with other personal wishes as one nears death, which, if not adhered to, have been shown to make a measurable difference in reported pain levels, mental well-being, and healthcare outcomes (Wachterman & Sommers, 2021).

Barriers

Existing literature on EoL planning and ACPs reveals that individuals experiencing homelessness are less likely than the general population to engage in ACP behaviors (Mittal et al., 2025; Sudore, Heyland, et al., 2017). However, recent studies have begun to point that gaps between desired and realized advanced-care plans are not rooted in a lack of desire to engage in the ACP process, but rather stem from systematic barriers. These barriers can include, but are not limited to, access to education and information, financial and social resources, bureaucracy, and geography (Kaplan et al., 2020). Often, these barriers are as simple as competing priorities and social isolation, to an inability to access trained and trusted medical staff (Kaplan et al., 2020; National Health Care for the Homeless Council, 2016; Sudore et al., 2018).

Studies have shown that the rate of engaging in ACPs is also strongly tied to the locality in which an individual most often resides. While studies have shown a relationship between geographic location and the rate of ACP engagement (Weldrick et al., 2022), they have not examined the relationship between ACPs and shelter status. With this in mind, variations between Continuums of Care (CoCs), which oversee homelessness care within their jurisdictions, can significantly impact access to documentation, healthcare, and medical/legal resources (U.S. Department of Housing and Urban Development, Office of Planning and

Development, 2022). However, current literature does not differentiate between unsheltered individuals (without fixed shelter) and unhoused individuals (with access to a vehicle), ultimately restricting our understanding of how geographic mobility intersects with the capacity to plan for one's own death. For example, it is common for unhoused individuals to work in different regions depending on the seasonal jobs they rely on, frequently crossing CoC boundaries (Bruder, 2018; Giamarino et al., 2022). While systems exist to facilitate information sharing between CoCs and enable a continuous care approach, individuals who do not regularly reside in CoCs with these systems may find their care discontinuous (Burt et al., 2002).

Framework & Theories

This study draws upon existing research into ACPs as a foundation for measuring informal and formal EoL planning behaviors. Because EoL plans can be understood as a subset of ACPs, previous studies provide invaluable insight into measuring and detecting EoL plans and potential third variables. This study will employ strategies developed in earlier studies, which incorporate the Social Determinants of Health framework (Office of Disease Prevention and Health Promotion, 2020). While this framework will not inform us of potential relationships and their direction or strength, it will aid in accounting for external variables such as geography, resource availability, and healthcare access.

By dividing participants into two groups (unsheltered & unhoused), this study aims to examine whether and how the availability of mobile temporary shelters (e.g., vehicles) affects EoL planning engagement. Previous studies suggest that geographic mobility and access to medical/legal resources all play a factor in the development of end-of-life plans and, therefore, must be accounted for and measured (Fewtrell et al., 2025; Wachterman & Sommers, 2021). This study aims to affirm and build upon these findings.

Research Questions

In light of the above discussion, my work aims to advance understanding of why and how homeless individuals engage in EoL planning. Moreover, this study aims to describe the general shape of thought regarding EoL planning in this often-neglected population.

However, my formal research questions are as follows:

1. *How does the experience of being unsheltered or unhoused influence end-of-life planning and attitudes surrounding end-of-life planning?*
2. *Are there significant differences between unhoused and unsheltered populations in relation to end-of-life planning?*

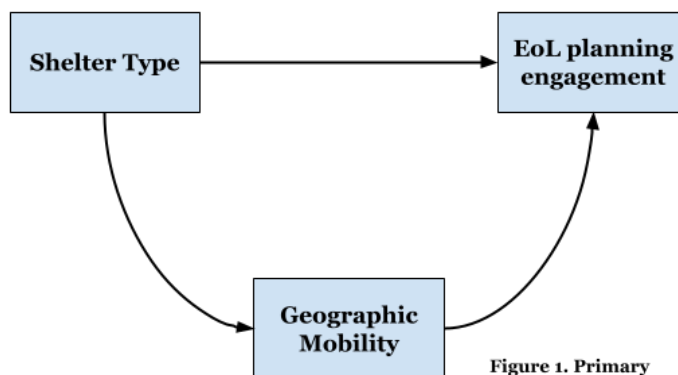


Figure 1. Primary Relationships of Interest

- a. *How does increased geographic mobility affect end-of-life planning?*

Expected Results & Hypothesis

1. *Both unsheltered and unhoused groups engage in less intensive and less extensive end-of-life planning than the general public.*

While this study's sampling frame will not include members of the general housed population, it will draw on results from numerous studies on the general shape of advance care planning in the general population, which measure specific behaviors that can be understood as part of EoL planning.

2. *An increase in geographic mobility will increase resource access; however, it will result in less resource usage.*
3. *It is expected that unhoused individuals will have greater access to economic resources, but less access to formal resources provided by CoCs.*

These are expected to originate from the more mobile population, which often travels between CoC jurisdictions and may avoid more advanced CoC communities for a myriad of reasons, such

as fear of detection or victimization (Whaley & Abbott, 2023). The differences between unhoused and unsheltered individuals are expected to stem from the nature of a mobile, unhoused population that crosses CoC jurisdictions and may therefore lack a coherent care continuum. As previously mentioned, many CoCs do not utilize any system that allows for communication with other CoCs, potentially leading to gaps in care (Burt et al., 2002).

4. *It is expected that several mediating variables will be present. For example, being unhoused may reduce access to healthcare professionals, resulting in lower end-of-life planning scores.*
5. *There will be extensive gaps between desired and realized end-of-life plans. It is expected that this will primarily stem from a lack of economic and legal resources.*

These last few hypotheses are essentially the same as those in previous studies, and, as previously stated, this study aims to confirm them.

Data Collection

Measures

Data will be collected through a select number of semi-structured interviews and an anonymous online survey. By employing these two methods, this study will achieve a greater depth of knowledge while reducing the likelihood that an individual will utilize a socially desirable answer set.

Multiple variables will be measured. The primary variables of interest are shelter type (unhoused/unsheltered), geographic mobility, resource availability/use(e.g., economic or legal), and EoL planning.

Shelter type will be measured using a multiple-choice filter question. Possible wording of the shelter type measure is “*Which of the following best describes your current housing situation?*” Possible answer choices include but are not limited to *emergency shelter, transitional housing, and couch surfing*.

Geographic mobility will be measured as the aggregated distance traveled. Individuals will be asked to list a number of cities or towns where they stayed for at least one month over the past year and their ‘major destinations’. Major destinations are defined as those at least 100 miles from the origin point. Post-collection, the total distance traveled will be determined based on the listed locations. The aggregated distance traveled will be used to report and measure geographic mobility.

Resource access and usage will be measured through questions inquiring about the legal, medical, or general services they have received. These will include mental health, legal, and financial services, among others. These will be measured through a series of select-all-that-apply questions, such as “*In the last 6 months, what services have you received? (Select all that apply)*”. Answer choices will include, but are not limited to: free legal services, paid legal

Survey & Interview Structure		
Section Title	Section Purpose	Time Span
Screening & Filtering	Questions will inquire into shelter status (unsheltered/unhoused) Questions will inquire into how long an individual has experienced their current shelter status.	1 Minute
EoL Planning - Legal	Questions will inquire into legal EoL planning such as designation of a next of kin and creation of a will.	3 Minutes
EoL Planning - Medical	Questions will inquire into medical EoL planning behaviors such as creation of a DNR.	3 Minutes
Perceived Barriers	Questions will inquire into perceived barriers to EoL planning.	5 Minutes
Resource Access & Usage	Questions will inquire into legal and medical resources one has access to. Questions will also inquire into geographic mobility.	5 Minutes
Demographics	Questions will inquire into necessary demographic data including ethnicity, income, and education level amongst others.	2 Minutes

services, free/paid medical care, an emergency shelter, *and government aid (e.g., SNAP)*.

Aggregated item scores will be used for analysis.

EoL planning will be measured using a series of questions that inquire about actions an individual has taken and their desires. Questions will inquire if a legal will has been created, if a power of attorney has been established, and if they have discussed their wishes with medical professionals or family members, among others. These will be a series of Yes/No questions on the same page to ensure that each item receives proper consideration.

Sampling Method

Given the inherent challenges of random sampling in the homeless population, the preferred sampling method for such research is convenience sampling, often with restricted samples (Richards & Kuhn, 2022). However, studies that employ this method frequently face significant challenges to external validity, as their samples are geographically and characteristically restricted (Richards & Kuhn, 2022). While some studies have used multistage cluster sampling, its use may raise questions of validity, as it could lead to significant systematic sampling biases due to differences in CoCs' ability and willingness to engage in comprehensive studies.

While this study will employ snowball sampling, survey recruitment will be facilitated through online forums and community networks frequented by homeless individuals. By using online forums, I hope to obtain a geographically diverse sample with a far larger sample size than is possible with traditional snowball sampling. A sampling frame of facilities to contact for further sampling facilitation will be generated from the Department of Housing and Urban Development [information exchange](#). If an individual service provider expresses that an individual would like to participate but lacks access to the internet, steps will be taken to make a paper version available.

On the other hand, current research points to a reduction in the gap in internet usage between homeless individuals and the general public (Rhoades et al., 2017), however, reliable

access to the internet and electricity remains a significant barrier (Galperin et al., 2020; VonHoltz et al., 2018). To account for these systematic barriers that may negatively affect the sample, semi-structured interviews are necessary to achieve a greater depth of knowledge. Data garnered from interviews will be used to provide a greater context than the often impersonal data surveys can yield. Interview participants will be drawn through traditional snowball sampling. A sampling frame of gatekeeper organizations for identifying interview participants will be created through multistage cluster sampling, from the State level down to the individual service provider level, using information from the Department of Housing and Urban Development [information exchange](#).

Participants will be divided into two groups to examine whether and how the availability of mobile temporary shelters (e.g., vehicles) affects EoL planning engagement. As previous studies suggest, geography, medical resources, and education influence the development of end-of-life plans and must be measured. This study aims to affirm and build upon these findings.

Survey saturation will be determined by the researchers when they believe no further data will be collected and that at least 190 unhoused and 190 unsheltered respondents have participated. A minimum of 30 semi-structured interviews will be required. Unhoused and unsheltered individuals will be sampled individually. Minimum sample sizes were determined using Cochran's sample size formula, with an estimated population homeless population of 770,000 (Soucy et al., 2025), an estimated proportion of .5, a confidence level of 95%, and a margin of error of 3%. A response rate of ~50% can be expected based on previous studies (Wright et al., 2023). If interview saturation cannot be achieved utilizing nested cluster sampling, traditional snowball sampling may be employed.

External Data

The data gathered through the survey and interviews will be combined with federal data reported by the Department of Housing and Urban Development on CoC resource allocation. By

combining these two data sets, it will be possible to specifically interrogate the differences local CoCs and geographic mobility can play in the formulation of an EoL plan.

The data will also be combined with datasets created and maintained by the Department of Health and Human Services that detail emergency and nonemergency medical resources at the county level. Because the county level defines an overwhelming majority of CoCs' geographic jurisdictions, this can give valuable insight into the medical resources available to homeless individuals. By utilizing these comprehensive and nationwide datasets, it will be able to paint a national and local picture of EoL planning and the network of effects that play a role.

Analysis

Interview Data Analysis & Processing

Thematic analysis will be used to identify recurring patterns and themes related to barriers, motivations, and values influencing EoL planning. A comparative analysis will explore differences between unsheltered and unhoused populations, with particular attention to regional policy variations among CoCs. It is expected that barriers will include discrimination (e.g., gender or ethnic), a lack of social resources, a lack of knowledge or time, among others. Through thematic analysis, the underlying patterns shaping and affecting EoL planning will be teased out. The coding scheme will focus on perceived barriers and planning behaviors (e.g., hiring an estate planner), amongst others.

Survey Data Analysis & Processing

Surveys will be processed as completed to identify systematic biases and unusable responses. It is expected that, due to the study's sensitive nature, many questions will remain unanswered. These missing values will be analyzed to identify systematic biases that can and need to be eliminated.

Surveys will also employ methods to detect answer sets and will be analyzed for usability. If it is found that an individual employed an answer set, the data in question will be promptly removed and destroyed.

Possible relationships to interrogate and the planned respective statistical tests are as follows:

1. Shelter Type and EoL planning - Student's T-Test
2. Shelter Type, Geographic mobility, and EoL planning- Moderated Multiple Regression or Two-Way ANOVA
3. Location, Resource Access, and EoL planning- Moderated Regression

A list of expected necessary statistical tests can be found [here](#).

Potential Impacts

As previously stated, research continues to reveal the links between healthcare access, medical debt, and homelessness (Bielenberg et al., 2020). Understanding end-of-life planning among these often-forsaken populations becomes increasingly essential. Improved EoL planning engagement could reduce healthcare costs associated with emergency care. It could also help align medical or social interventions with an individual's wishes. All too often, individuals are not given a death they wish for, but one they can afford or easily obtain (American Psychological Association, 2010).

These findings can show local CoCs and homeless service providers where policies block homeless individuals from planning for care and death. Including individual perspectives in CoC planning can improve health outcomes and create more humane, efficient service models. Ultimately, this study seeks to illuminate how the experiences of geographic mobility, precarity, and exclusion shape the most personal yet universal human concerns.

Ethical Considerations

Because this study involves individuals experiencing homelessness, ethical safeguards will be essential. These safeguards include strictly voluntary participation and informed consent obtained before any data collection. All participants will receive a clear explanation of the study's purpose, as deception is not deemed necessary, their right to withdraw at any time, and the measures taken to protect their confidentiality.

Completed interviews and surveys will employ a participant ID number rather than identifiable information such as their name. Moreover, information on resources will be made available upon completion or upon electing to end the survey or interview early. These resources will include, but are not limited to, CoC information, federal HUD program information, and national nonprofits.

It is planned that no incentive or compensation will be offered for participation. Because of the limited economic resources available to individuals experiencing homelessness, it can be expected that any monetary compensation can provide perverse incentives for participation.

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