



Social Model Hospice: Providing Hospice and Palliative Care for a Homeless Population in Salt Lake City, Utah

Francine Bench Jensen, PhD, RN ○ Deborah Thorpe, PhD, APRN

Health care for the homeless population is a complex challenge and represents a significant gap in care, particularly for those at the end of life. Hospice care may be desired but is rarely an option for people without residences, social support, and payment sources. Social model hospice is a unique paradigm of care delivery that offers a viable solution to make hospice and palliative care possible for this population. In this historical report from interviews with early organizers, prior and current leadership (n = 6), the evolution of The INN Between in Salt Lake City, Utah, is described. In 2010, The INN Between was conceptualized as a nonprofit community effort addressing this need to provide an alternative to people dying unsheltered. After 5 years of planning, it opened in 2015 and has grown to become a comprehensive community resource for homeless medically frail and terminally ill individuals. Recommendations for establishing social model hospices are made: key strategies include identifying stakeholders dedicated to alleviating end-of-life homelessness needs, doing a formal needs assessment to identify community resource deficits, and forming mentoring relationships with established programs. Social model hospice is a viable way of meeting the end-of-life needs of many communities' most vulnerable residents.

KEY WORDS

end of life, homeless, hospice, social model hospice

Providing hospice and palliative care to individuals experiencing homelessness is a complex challenge and highlights a significant gap in the current health care system in the United States. People without stable

housing suffer disproportionately with diseases such as liver cancer, cirrhosis, chronic obstructive pulmonary disease, renal disease, and many types of cancers,¹ which require advanced care and management at the end of life to avoid pain and suffering. The average age of death for those experiencing homelessness is around 53 years,¹ which is far younger than the national average of 76 years.² This confluence of age and disease leaves individuals without access to end-of-life (EOL) services through the Medicare Hospice Benefit (MHB) because of age eligibility, appropriate diagnosis to trigger services (6 months or less to live), and/or the complexities of applying for the program.³ Not having stable housing, in most circumstances, precludes or significantly limits hospice services being delivered to them, as a person's residence is where services are provided with the expectation of assistance by family or close friends^{4,5}; routine home care accounts for 98.2% of all hospice services.⁶ Another barrier individuals experiencing homelessness may encounter is that their interpersonal relationships are often strained,⁷⁻¹¹ which can complicate having caregiver support upon which hospice services are premised.⁵ When these factors converge, individuals are ineligible to receive in-home hospice services and are therefore at risk of dying in hospitals, alone, and/or unsheltered, highlighting a gap in the type of care they can access.

Determining the scope of who is affected by homelessness has been and continues to be a challenge to quantify. In some states, collecting statistics helps community leaders identify trends to guide decision-making and allocation of funding,¹² and a national Homeless Management Information Systems database is also maintained. In 2021, nationally there were 13 801 homeless individuals.¹³ These numbers are likely an underrepresentation because only homelessness affiliates whose funding sources require them to contribute data are obligated to report to government collection sites.

To understand the needs in Utah, in 2022 Utah's point-in-time count declared 3556 persons experiencing homelessness on a given night who were in temporary housing or were unsheltered.¹⁴ However, the extent of the need for EOL care in this population is not a nationally collected statistic, nor is it collected by some states. In some communities,

Francine Bench Jensen, PhD, RN, is associate professor, Utah Valley University, Orem.

Deborah Thorpe, PhD, APRN, is founder and former nursing supervisor, The INN Between, Salt Lake City, Utah.

Address correspondence to Francine Bench Jensen, PhD, RN, with 800 W. University Pkwy, MS 172, Orem, UT, 84058 (francine.jensen@uvu.edu).

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a candlelight vigil is held each December sponsored by homeless advocates to publicly acknowledge individuals who have died homeless during the year, thus providing a de facto count of local homelessness deaths.¹⁵ Vigils held in Salt Lake City, Utah, reported 94 individuals died in 2019,¹⁶ 117 in 2021,¹⁷ and 159 in 2022.¹⁸ Some of these individuals died because of trauma, overdose, or exposure, whereas others died of chronic, life-ending conditions that could have been treated with hospice services. In 2023, in Salt Lake City, the medical examiner began adding housing status to individuals' death information, which will allow for collecting more precise information of the EOL needs of individuals experiencing homelessness.¹⁸ Gathering quantifiable information is one way homeless services leaders can track ongoing needs and fine-tune EOL support for individuals.

HISTORY OF SOCIAL MODEL HOSPICE

A unique care delivery paradigm patterned after traditional hospice, called social model hospice (SMH), increases access to hospice care for people without stable housing or social networks.¹⁹⁻²⁵ The concept was proposed in 2015¹⁹ and further delineated with antecedents, attributes, and consequences in 2021.²⁰ Proponents of SMH emphasize that everyone deserves to experience death with dignity, a perspective that promotes social justice by increasing access to equitable EOL care.¹⁹⁻²⁵ The origin of the SMH model can be traced to the HIV/AIDS epidemic during the 1980s to 1990s, when communities of interest came together to ensure individuals who had been socially ostracized because of the stigma of having HIV/AIDS would not die alone.²⁶⁻²⁹ Initially, most of the population affected were gay men, men who had sex with men, and intravenous drug users; their average age of death was 39 years.²⁶ These disenfranchised individuals had very little medical, social, or personal support as their diseases advanced, and these grassroots SMH efforts allowed them to experience nonmedicalized deaths in supportive, home-like environments.²⁹ In the late 1980s with the advent of anti-retroviral drugs, HIV became a chronic, manageable illness, so acute needs for EOL care began to wane. Some locations providing SMH care closed, whereas others began filling a niche for similarly disenfranchised people, such as those without permanent housing, and are still operating today.³⁰⁻³²

Delivering SMH care is not duplicated by existing community services. It has unique antecedents experienced by people who present a need for SMH: a personal and financial resource crisis; unmet needs outside the scope of traditional hospice requiring the assistance of family or friends and a location for care provision; and a desire to experience death using hospice services (Figure 1).^{19,20,25,31}

- Home settings with community-supported, grassroots origins.
- Established as non-profit organizations.
- Dedicated to caring for dying individuals in need, by providing 24-hour services when dying at home is not an option.
- Compassionate EOL care provided by paid and volunteer caregivers.
- Collaboration with medical hospice agencies responsible for care provision.
- The cost of housing is free or on a sliding-scale, as applicable; not covered by Medicare, Medicaid or private insurance.
- Unique care that does not duplicate existing community services.

FIGURE 1. Antecedents of social model hospice care.²⁰

Variations exist between traditional in-home hospice care and SMH care. The MHB delivers care in home or home-like settings and is financed through Medicare or private insurance.^{4,5} The hospice services are provided by contracted hospice agencies, augmented by a combination of paid caregivers, volunteers, or individuals from people's social networks who help deliver the care. In contrast, the SMH model offers community-based care at freestanding locations where the individual becomes a resident, often called SMH homes (SMHh).¹⁹ Housing and food are provided free of charge by the nonprofit SMH organization. The financial costs of receiving hospice care are covered through donations or until the approval of the MHB. At The INN Between (TIB) in Salt Lake City, being unstably housed is the trigger for entry for residents, once a life-limiting diagnosis is made (oral communication, D. Thorpe, January 8, 2020). A recent analysis of 500 residents served in 3 SMHh in New York State during a 15-year period reported 1% as homeless.²⁴ The authors are aware of 4 homes serving a primarily homeless clientele as TIB does, and 2 more are set to open³³ (personal email communication, B. Smith, email communication, February 4, 2023). Residents from other SMHh experienced a loss of caregiver support and entered care.^{19,20,22} Further research on the characteristics of SMH residents in the United States is needed to inform a comprehensive description of who is served by SMHh. Regardless of the exact points of entry, care delivered through SMH overcomes barriers to receiving hospice care, extending it to those who want traditional hospice care but do not meet the conditions to do so. Figure 2 compares MHB and SMH elements for care delivery at one location serving a predominantly homeless population in Salt Lake City^{4,5,21} (oral communication, D. Thorpe, January 8, 2020).

The Omega Home Network, a nonprofit organization dedicated to promoting SMHs, listed 61 active locations in the United States, with several others in development,³⁴ whereas others reported more than 80.³⁵ Sizes of homes range from 3 to 25 beds.³⁴ It is likely there are other SMHh in the United States, given the grassroots origins of communities meeting local needs.

The academic literature describing SMH is growing.^{19-24,35,36} Yet, there is little information in the academic literature for communities considering starting SMHs. The purpose of this article is to share a historical report of the development process of 1 SMH, TIB in Salt Lake City, in order to assist

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Elements of Hospice Care	Medicare Hospice Benefit Model	Social Model Hospice Model in Salt Lake City, UT
Location of Delivery	-Provided at a private place of residence	-Provided at the SMH location where the individual has become a resident
Payment sources/payor	-Private insurance -Medicare Hospice Benefit -Out-of-pocket	-Community donations or fundraising -Foundation or grant money -Medicare Hospice Benefit, once approved (paid directly to hospice providers, not the SMH)
Personal support system that partners with the hospice company	-Family including family-of-choice, friends, trained hospice volunteers	-Trained SMH volunteers -No-One-Dies-Alone (NODA) volunteers -Support staff -As available: family including family of choice; friends; "street families"
Hospice care provider	-A contracted hospice agency	-A contracted hospice agency

FIGURE 2. Comparison of care delivery between Medicare Hospice Benefit and social model hospice delivery in Salt Lake City, Utah.

other community leaders interested in replicating or adapting this model. Interviews were done as part of a larger case study with 6 individuals in leadership roles, two of whom were early organizers,²¹ and were approved by the University of Utah's institutional review board. Highlighting issues and challenges an SMH faced during start-up and operations may prepare other communities for a successful journey, helping their most vulnerable residents receive EOL care.

THE INN BETWEEN ESTABLISHED IN SALT LAKE CITY

The SMH called TIB was conceptualized in 2010 as a grassroots effort, with an initial vision of providing a safe and comfortable home to ensure that no one died homeless and alone without health and spiritual care in Salt Lake City.^{36,37} Since opening its doors in 2015, TIB has provided death with dignity for 108 individuals.³⁸ During fiscal year 2021-2022, 104 unique clients were served with 11 770 nights of stable housing. Of the 104 individuals, 67 were classified as medically frail, 37 were classified as terminally ill, and 15 experienced death with dignity at TIB.³⁸

It took the planning of several community organizers and stakeholders from 2010 to 2014 before the fledgling organization was formally incorporated as a 501(c)(3) charitable organization. After a long search for a suitable property, it began operations in 2015 in a convent building attached to a former Catholic elementary school. With an initial capacity of 14 residents that was soon filled, adjustments were quickly made to accommodate 17 residents. The focus of operations was to provide a safe and supportive location where residents could receive appropriate EOL care from existing community hospice and home care agencies, augmented by staff and volunteers. As more needs became known and the demand increased, TIB expanded its focus to include respite and recuperative care for medically frail individuals without stable housing. These individuals

are not yet considered terminally ill and lack a location to prepare for or recover from medical treatments such as surgery, cancer treatment, and wound management. The words *respite* and *recuperative care* are distinct from the context of respite care in the MHB setting that provides respite for caregivers. In the homeless context, respite is provided to the homeless individual as relief from dealing with their medical problems on the street or unsheltered.³⁹

This broader focus necessitated a move to a larger facility, and in 2018, a former skilled nursing facility was purchased allowing for a capacity of up to 50 residents, with 25 beds for assisted living and 25 for independent living. This size demarcates TIB as one of the largest SMH facilities in the United States.³⁴ The recuperative care program fits well under the umbrella of palliative care. Many palliative care residents, particularly those with advanced stages of diseases such as cancer and heart disease, go on to become hospice candidates, and they transition to EOL-focused care with the advantage of remaining at the same residence.

Adding the assisted-living focus grew out of the need to address more complex needs of the residents. Subsequently, the organization became licensed as a level II assisted-living facility by the state of Utah. This now allows for assisting individuals with their activities of daily living, supervised by a registered nurse and paid certified nursing assistants. The addition of nursing staff facilitates medication management, which is a significant need in this population. Most residents have chronic medical conditions and historically have had poor compliance with treatment. Most are uninsured or underinsured and therefore have difficulty paying for prescribed medications. When they do have medications in their possession, the medications are often subject to theft because of unprotected living conditions and the prevalence of substance abuse.⁴⁰ Inconsistent follow-up for medical care is a known characteristic of the population and often takes place in emergency rooms. Individuals have a limited understanding of the medicines prescribed. This contributes to ineffective medication regimen adherence and competes with access to food and shelter as a priority.⁴¹ The SMH structure helps to overcome this gap by providing residents consistent, supervised medication management and follow-up with care.

CONSIDERATIONS AND CHALLENGES OF ESTABLISHING AN SMH

Successful creation of an SMH requires considerable planning and organization within communities. Key experiences including some challenges TIB overcame are presented next.

Initial Steps: Planning, Mission, and Vision

The INN Between began with 2 individuals, a nurse practitioner and a parishioner working in the food pantry of St Paul's Episcopal Church in Salt Lake City, who saw a

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community need to provide a home where individuals with stable housing could receive palliative care at the end of life. After gaining support from the church, they began to identify stakeholder allies willing to commit their time and expertise on behalf of this population. They convened an informal group that included homeless service providers, hospice agencies, clergy, social workers, and leadership from the Utah Hospice and Palliative Care Organization. The Fourth Street Clinic, the leading provider of homeless health care in Salt Lake City, was an important supporter as the project was conceptualized. Discussions among these groups took several years; however, a vision and plan came together.

As SMHs are set up as nongovernmental organizations, the 501(c)(3) application was sought and granted in 2014, and fundraising began with a simple soup supper, in keeping with the nature of the target population. These initial funds provided the basis to begin negotiations for rental of a property, and an executive director was hired to lead the efforts to formally establish the program.

Overcoming Zoning Issues

Finding a location where care could be delivered was high on the list of needs. All potential properties needed renovation for accessibility. A former school and convent were identified as most promising. Initially, it was felt that the school building would be more accessible for residents because it was on 1 level, but the bathrooms would take considerable cost to renovate for adult use. The convent building had sleeping quarters on the second floor accessible only by stairs. Eventually, office space was put in the school area, and the convent became the residential area.

Negotiating the myriad city regulations and zoning ordinances was a major challenge. It became clear that the proposed hospice program did not fit neatly into current city zoning categories or definitions. After negotiations and a city council hearing, the proposed facility was classified as *eleemosynary*, a designation used for charitable organizations that allowed for occupancy of the convent building.⁴²

Community Assimilation and the Not in My Back Yard Syndrome

A common phenomenon encountered by agencies looking for solutions to homeless needs, known as the “Not in My Backyard” (NIMBY) syndrome, is resistance from neighbors and businesses fearing the incursion of crime, drugs, and the increased presence of those experiencing homelessness in neighborhoods. Anticipating the need to garner support from the neighborhood during the planning stages, efforts to engage those who lived closest to the property were begun. As the first property was adjacent to a Catholic church, engaging with the parish priest provided key access to local community members. In addition, organizers sought out the city council representative for the area for support.

Despite efforts to anticipate neighborhood resistance, there was a significant NIMBY response from neighbors. The city council representatives received calls from vocal constituents, which ultimately led to a review of zoning regulations by the city council. A city council hearing was convened, at which attendee supporters of TIB significantly outnumbered the opponents present. After much discussion, the city council approved the plan for a location.

The second site was zoned as a skilled nursing facility, so no zoning changes were required. To preempt concerns before moving, board members canvassed the neighborhood providing information about the mission and day-to-day function of the facility. Several town-hall meetings were convened, including participation from the local city council representative, which allowed for open discussion and education regarding the nature of the program. To assuage fears, emphasis was placed on the fact that a home and stable living environment was being created, differentiating it from a shelter. In addition, residents would agree to a code of conduct and house rules to remain in residence, which included maintaining a drug-free, sober living environment.

Despite such reassurances, it was difficult to completely alleviate the apprehension that there would be negative impacts on the neighborhood. Organizers found it was critical to establish open, ongoing communication with neighbors by providing 24-hour facility contact information, prompt responses to questions or concerns, and assurances that law enforcement support was in place. After the meeting, there was substantial outpouring of support for TIB from the neighborhood, a “Yes in My Backyard” (YIMBY) coalition was formed, and several neighbors signed up to volunteer. The YIMBY group also sponsored a campaign encouraging neighbors to place YIMBY signs in their yards, demonstrating visual support for TIB throughout the neighborhood.

Volunteer Support

Involving volunteers is fundamental to the community-driven origins of SMHs, and a strong volunteer program is essential to operations.²¹⁻²³ A staff member oversees volunteers at TIB who fill a variety of roles that would be performed by paid staff in other settings: house cleaning, organizing donations, laundry, meal preparation and serving, activities for residents, and transportation to medical appointments. Trained volunteers assist with activities of daily living for residents, and many become trained to participate in the No One Dies Alone program,⁴³ where volunteers sit at the bedside when a resident is actively dying. In addition, TIB supported EOL doula training for a staff member who helps nursing staff and volunteers when the No One Dies Alone program is activated for a resident. The EOL doula provides direct support for the resident: they ascertain

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residents' final wishes, ensure any cultural and spiritual needs or practices are honored, and identify people the resident would like with them in their final hours.^{44,45} Volunteers also provide financial benefits to the organization. In the most recent fiscal year report, more than 3053 volunteer hours were logged,³⁸ with a reported savings of \$88 500 to the organization.⁴⁶

Other Early Considerations

Other considerations for establishing SMHs include (1) convening a dedicated stakeholders/community advisory panel, (2) doing a formal community needs assessment, and (3) establishing a mentoring relationship with an established SMH.

Stakeholders and Creating Coalitions

It is advantageous to convene a community advisory panel of stakeholders at the earliest opportunity to identify available resources and/or deficits in the community. Possible stakeholders with relevant alignments are hospice organizations; hospitals (first-line providers for health care services for this population who have a vested financial interest in alternative EOL care); other homeless services providers, directors, or staff (ie, from shelters, the local department of health, Health Care for the Homeless clinic, and others); and local religious groups and charitable organizations that are ideologically aligned with serving this population. Other stakeholders could include representatives from the state legislature, city council, and community entities. State and local governments may become major funders in subsequent years, and their participation can provide vital funding over time from national financial sources administered at the state level. Topics for the advisory panel may include identifying funding streams, possible locations where a facility could be located, and options for provision of hospice care. These relationships may segue into advantageous coalitions that support future operations when facilities open.

Performing a Needs Assessment

During the conceptualization stage performing, a community needs assessment involves stakeholders and communities of interest that allows for their early input. The needs assessment should explore the role of homeless shelters in the community, the number of medical beds in temporary shelters with historical occupancy data, and what EOL care options are available for this population. These data can then be used to describe how the SMH would fill this gap in care and to inform like-minded community partners and potential donors of future support opportunities.

Establishing a Mentoring Relationship

Mentoring other communities is a core value of SMH proponents and facilities.²⁰ Establishing a mentor relationship

with an operating SMH organization is invaluable for those contemplating starting SMHs, as mentors can share their experiences about the pitfalls and challenges of startup, including navigating state and local regulations, addressing zoning issues, and working through NIMBY/YIMBY concerns. Mentors' counsel to fledgling organizations will forge bonds across communities and can accelerate the process of opening new facilities. For example, TIB mentored Joshua's House, which has faced many of the same obstacles as they approach opening their facility.³³ This collaboration resulted in a major news story highlighting both efforts.⁴⁷

Forming a Nongovernmental Organization (NGO) With a Board of Directors

As an integral part of NGO structuring, a board of directors has the responsibility of strategically planning for the organization's future by adopting sound ethical, legal governance and financial policies so the organization has adequate resources to fulfill its mission.⁴⁸ Other responsibilities may include oversight of personnel and programming, upcoming legislative concerns, and fundraising efforts. The composition of board membership should bring a depth and diversity of professional experience that may include public health, social work, business management, hospital board membership, nursing, and medicine (eg, emergency, trauma, and hospice), as well as legal expertise. This experience will provide unique perspectives about the continuum of care specific to homelessness issues.

Board members should be oriented to the expectations of board membership, such as attending meetings, taking part in community events, establishing community partnerships, and fundraising. Protocols and policies should be readily accessible to board members to guide them in their roles. They should tour the facility, so they are familiar with the location of care, meet staff, and have a firm basis for advising on issues.

Funding Considerations and Partnerships

Strategizing future funding needs is a major responsibility of board members. Funding may be secured from local organizations: city and state government grants, hospitals, and other medical care providers. Establishing working relationships or partnerships with hospitals is key, particularly with staff responsible for discharge planning and case management. For example, TIB collaborated with one of the regional hospital systems, Intermountain Health Care, which has provided both financial support and pro bono care for some residents at TIB who were ineligible for state or federal resources such as those who are undocumented (oral communication, K. Mieremet, January 20, 2020).

Other interested contributors may be local business, charities or foundations, and spiritual/religious-based entities. Extending invitations for board membership to stakeholder



organizations may be one way to cultivate future funding streams and partnerships with organizations that have complementary missions. In addition, developing partnerships with local food banks and charity shops for donations of bedding or clothing can save on operational costs. These relationships may take time to develop but further overall successful operations.

The Use of Publicity

Publicity raises community awareness of initial and ongoing needs of SMHs, and organizations should consider a proactive strategy to form relationships with news staff who consider stories about this population and SMH as part of their special interest focus. Positive publicity could diffuse NIMBY efforts while educating the public about the mission and facility needs. Publicity can be a recruiting tool for volunteers and future employees.²¹

DISCUSSION

The lessons learned from the start-up of TIB can guide other interested communities in beginning an SMH to address their local homelessness needs. The INN Between overcame several hurdles to start an SMH. Its primary service population is individuals experiencing the nexus of homelessness and EOL time frame; it provides a location where hospice care can be delivered, a way to pay for care through donations until MHB is secured, and a ready social network of individuals who assist hospice agencies with individualized care. Now as a recognized and established part of the community, their census has risen as more providers refer clients in Salt Lake City. They are providing compassionate, EOL care for approximately 50 people each year who otherwise would have died unsheltered or without hospice services in a more medicalized setting.³⁷

Communities can consider the impact that SMHs could have on their homeless populations. Interested communities can take several initial steps as they prepare by establishing a mentor relationship with an existing SMH, connecting with the Omega Home Network³⁴ for further guidance, performing a community needs assessment, setting up a 501(c)(3) organization, and beginning to fundraise. Identifying stakeholders and creating partnerships and coalitions with like-minded entities can generate early and ongoing support within communities. Other operational suggestions include being prepared to address NIMBY resistance; creating a strong, organized volunteer program; and accessing local resources such as food banks and charity shops to assist organizers with crucial first steps toward opening.

Future research is needed to explore characteristics of residents more broadly, and specific needs for individuals without stable housing and those who lose caregiver support and are therefore unable to remain at home. Regional

needs or usage may vary as well as specific services and those served (ie, geared more toward a homeless population vs individuals who have lost caregiver support). Additional research can inform the scope of SMH care and the experiences of people who receive it and add to the growing body of literature about SMH.

CONCLUSION

Social model hospice ensures hospice care can be delivered to people who have barriers to receiving hospice services, particularly for those who experience homelessness and have limited social networks to help with care provision. The INN Between is meeting the needs of individuals in Salt Lake City, for EOL housing, emotional and physical support, and payment of services. Using the lessons learned from TIB, communities can explore this option for some of their most vulnerable residents at the end of life. Social model hospice is a viable, community-led approach filling a humanistic gap for individuals where barriers exist to accessing traditional hospice and palliative care services.

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