Social Model Hospice Homes: Bridging the Gap in End-of-Life Care Delivery

Kliewer A, BA[1], Farrar, H, PhD, RN, BC, CNE[2], Scott, K BSN, RN, CHPN[3], and Clark J, MD[3]

[1]University of Oklahoma College of Medicine; [2]University of Oklahoma Fran and Earl Ziegler College of Nursing; [3]Clarehouse Tulsa, Oklahoma

COLLEGE OF MEDICINE
The University of OKLAHOMA HEALTH SCIENCES CENTER

Introduction

People prefer to die at home, if given a choice. However, data show that less than half of hospice patients get to do so, as many lack the social resources needed for end-of-life (EOL) care to be supported at home.

The Social Model Hospice Home (SMHh) is an emerging model of care which offers an option for individuals whose EOL care cannot be fully supported by their available social network.

SMHh is a community-supported home staffed with round the clock caregivers dedicated to closing this social gap in EOL delivery.

Objective

This study aimed to enhance and clarify the reasons for successful outcomes of the SMHh concept.

Methods

This project was a qualitative, descriptive cross-sectional study of experiences of persons impacted by social model hospices (SMHs). This method begins with sampling, progresses to data collection through semi-structured interviews, and ends with data analysis.

Interviews were completed in person, except for two, with one by phone and with one participant answering questions through email. Comparison groups included persons experiencing EOL at the SMHh and their family members, significant others of previous patients, staff, volunteers, board members, and members of the community. A total of 23 participants were interviewed for this study.

Participant sampling was pulled primarily from Clarehouse, with some participants from other sites across the Omega Home Network (OHN).

The Institutional Review Board of the author's institution deemed the study exempt and the project was approved by the board of directors of Clarehouse. Interviews were completed over the course of two months.

Data used for analysis included detailed notes from semi-structured interviews, observations, and physical documents. After each interview, the method of constant comparison took place in which the primary author assigned codes to repeated key words or phrases. When these key words and phrases were seen across the interviews, theoretical saturation was reached, and the patterns developed into major themes.

Results

From the data, analysis yielded five major themes describing the experience fo the SMHh concept and its effectiveness in delivering high-quality EOL care: (1) physical attributes of the home (2) volunteer base; (3) attention to detail; (4) structure of accountability; and (5) practice of compassionate honesty.
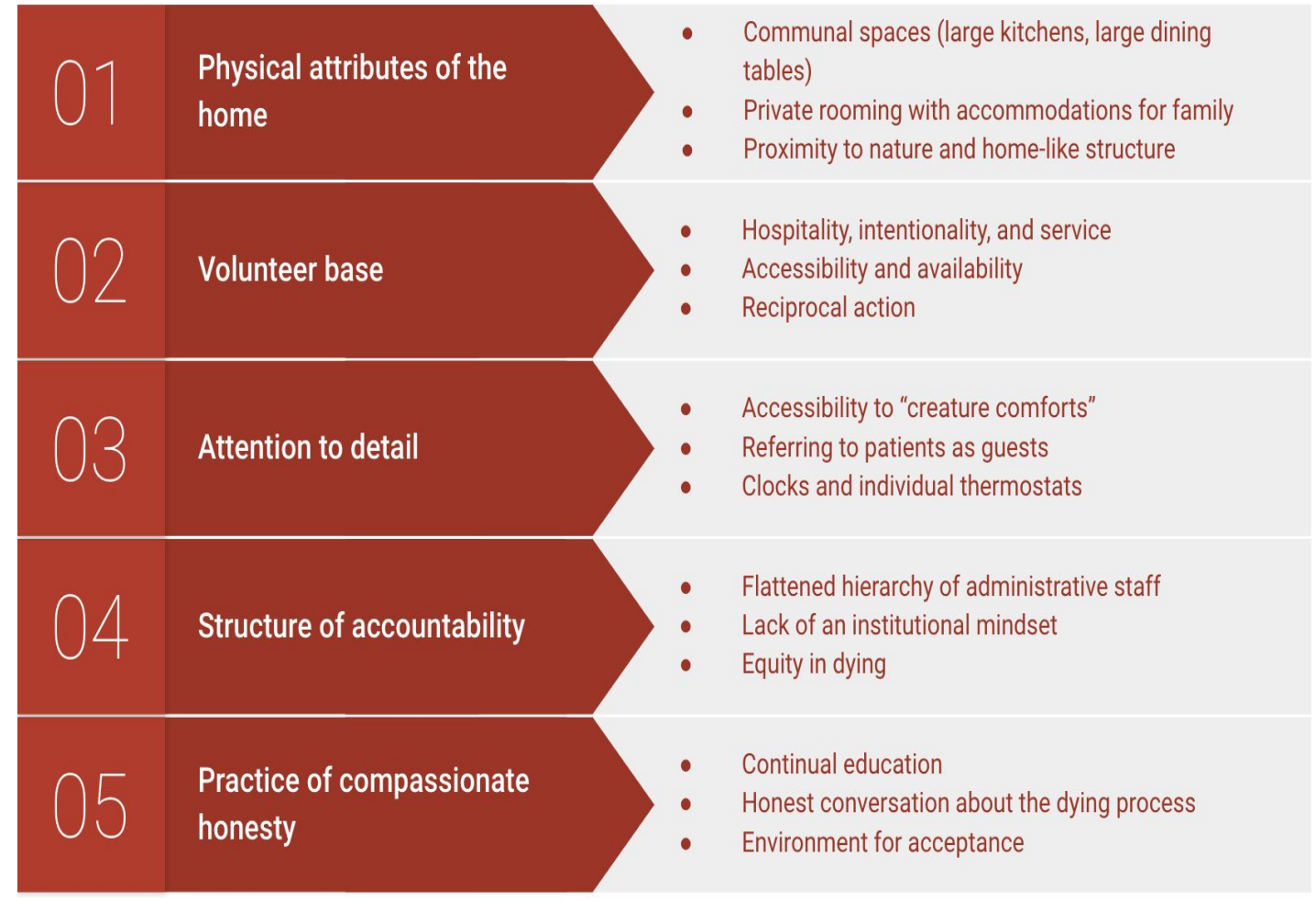

01	Physical attributes of the home	• Communal spaces (large kitchens, large dining tables) • Private rooming with accommodations for family • Proximity to nature and home-like structure
02	Volunteer base	• Hospitality, intentionality, and service • Accessibility and availability • Reciprocal action
03	Attention to detail	• Accessibility to "creature comforts" • Referring to patients as guests • Clocks and individual thermostats
04	Structure of accountability	• Flattened hierarchy of administrative staff • Lack of an institutional mindset • Equity in dying
05	Practice of compassionate honesty	• Continual education • Honest conversation about the dying process • Environment for acceptance

Figure 1. Five Major Themes.

Discussion

The study highlights five main themes. Based on interviews, conversations, and observations collected, these elements were deemed important and affirmed an association between attributes of SMHh and reports of a positive EOL care experience. This reinforces the viability of the SMHh concept as an innovative solution to bridging the gap in the delivery of effective EOL care.

The dominant themes work together to create an environment that is characterized by hospitality, grace, and compassion. In particular, the physical attributes of a home-like setting as "not-like" a nursing home or hospital setting were associated with a positive report.

Because having a physical space that is not a medicalized facility is a key concept of SMHh, it is significant to quantifiably affirm the association of the home-like environment with positive EOL care outcomes.

Our study noted the empathetic traits of accessibility and meeting needs without being asked were an important aspect of the positive EOL experience.

Participants reported the freedom to bring their favorite foods, visit with pets, and display personal objects provided an avenue of nonverbal communication, which allowed SMHh personnel to engage in unique aspects of a guest's and family's life.

Honest, straightforward education positions the SMHh team to walk alongside the guest and family as a guide and companion, further personalizing the experience. This additional layer of intentionality and presence may have a unique impact on the positive experience in EOL care and needs further exploration.

Acknowledgements