

ABSTRACT

The Secret Sauce of Clarehouse: A Grounded Theory Analysis of Social Model Hospice

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The purpose of this research is to enhance and clarify the reasons behind the successful observations and responses of guests and family members throughout Clarehouse's social model hospice program. Social model hospice is a 24 hour, community-based home for individuals whose end-of-life care cannot be fully maintained by their available support network (Grant & Scott, 2015). This thesis specifically uses the classic Grounded Theory methodology, a qualitative research method. Through a series of semi-structured interviews with staff, volunteers, community members, family members, and guests, distinct patterns began to emerge. These themes include the physical attributes of the home, the volunteer base, the attention to detail, the structure of accountability, and the practice of compassionate honesty. Each factor or "ingredient" is a necessary element in creating the "secret sauce" of Clarehouse.

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THE SECRET SAUCE OF CLAREHOUSE: A GROUNDED THEORY STUDY
OF SOCIAL MODEL HOSPICE

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DEDICATION

To Clarehouse, thank you for welcoming me with open arms. And to my parents, who have encouraged me from the beginning.

INTRODUCTION

It is easy to perceive the loudness and speed of life. It takes much more strength to find stillness and quiet. Often, it is only when we are forced to stop that we truly appreciate the world around us. Nestled in the heart of Tulsa, Oklahoma is a beautiful, ten-bedroom home. The property is surrounded by a small creek, large, looming trees, and landscaping that creates a sense of escape and isolation. Nearby, cars rush by on their way to their destinations, but inside this home the complacency of the everyday life is replaced with intentionality and understanding. The inhabitants of this home are dying.

Inside the building, an almost paradox of feelings is felt. Sadness is present, but it is also accompanied by feelings of hope, love, and tranquility. The atmosphere is not dark and dreary. Rather, the tall ceilings, open windows, big kitchen, hardwood floors, couches, and art create a space that it is warm and inviting. The sound of life fills the house. Clarehouse, a community based home that provides end-of-life care, is a refuge for families and individuals in the midst of a terminal illness. In order to best understand what Clarehouse is, it is important to have a basic understanding of the desires of people at the end of life, hospice, and how it is utilized throughout the United States.

Research highlights that people want to die at home if given a choice (Gawande, 2014; Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). Regardless of this desire, in 2018 less than 50% of the deaths in the United States occurred with hospice care (*NHPCO Facts and Figures*, 2018). Along with this, researchers found that only 48.2% of individuals with hospice die at home, and 51.8% of individuals die in a nursing facility, acute care hospitals, or hospice in-patient facilities (*NHPCO Facts and Figures*, 2018). This can be due to many factors including but not limited to: complicated care,

aggressive life-prolonging treatment, lack of a support system or caregiver, etc. (Teno, Casarett, Spence, & Connor, 2012; Teno et al., 2007). While the reasons are plentiful, the unfortunate truth is that being at home may not always be a possibility.

Hospice provides compassionate, comfort care for those with less than six months to live (*NHPCO Facts and Figures*, 2018). This care addresses spiritual, psychological, emotional, and physical needs (*NHPCO Facts and Figures*, 2018). Currently, hospice throughout the United States is based on the medical model of the Medicare Hospice Benefit (MHB). The MHB includes four types of primary care: routine home care, inpatient respite care, continuous home care, and general inpatient care (*NHPCO Facts and Figures*, 2018). Within the MHB, the family acts as the primary caregiver for the individual receiving end-of-life care. Unfortunately, due to various circumstances this can often result in high caregiver burden¹ (Grant & Scott, 2015).

In 2011, the concept of social model hospice was presented throughout the literature by Sarah House in Santa Barbara (Jones, 2011). Social model hospice is “a community home with 24-hour care, accessed when care needed to die at home exceeds an individuals’ support network of family and friends.” (Grant & Scott, 2015 p. 456). Each home is non-profit and falls outside of government health care regulation. SMH homes are not hospitals, nursing homes, medical hospices, or medical facilities.

Social model hospice and *traditional medical hospice* are two separate entities that work together to help facilitate a “good” quality death. SMH is the environment and

¹ Though the term “caregiver burden” is an objectionable term to many clinicians as well as some family caregivers, it is widely used in the literature to denote the emotional distress experienced by some family members as they care for seriously ill loved ones. The term seems to be increasingly popular in the peer-reviewed literature. A PubMed search in early 2020 revealed 3,261 citations in the literature in all years prior to 2011 and 6,594 citations since 2011. Of the nearly 6,600 citations in the last nine years, more than 68% are in articles published in the last five years.

hands-on-care; whereas, medical hospice programs are the case managers (Grant & Scott, 2015). SMH does not duplicate the services of hospice programs; rather, they work in conjunction with them.

The primary exemplar used throughout this study is Clarehouse. Formed in 2001, it seeks to address the social crisis accompanied with the dying experience throughout the Tulsa community. Since its creation, Clarehouse has moved and expanded from a tiny three bedroom facility to a ten bedroom home. Clarehouse equally seeks to comfort the dying individual or “guest” and their family (Grant & Scott, 2015). While it is not a requirement for other social model hospice homes, Clarehouse employs one-licensed practical nurse. Along with the nurse, caregivers also make up the 24/7 paid staff (Grant & Scott, 2015). Caregivers can be certified nursing assistants, home health aides, or laypeople trained by Clarehouse (Grant & Scott, 2015).

In 2014, a group of researchers evaluated families—primary caregivers—regarding their experiences immediately prior, during, and following their stay at Clarehouse. Based on data collected, they found that Clarehouse relieved the physical suffering of guests; allowed guests and their caregivers the experience of a “good death”; lifted caregiver burden; improved caregiver well-being (Simonet, & Narayan, unpublished data, 2014). In spite of scattered research studies analyzing the benefits of SMH on the guests and families (Stuart, 2015), questions remained about the reasons behind the results. This study seeks to interview a wide variety of stakeholders to better learn what makes this social model hospice (SMH) work; in other words, what is the “secret sauce” of Clarehouse? The “secret sauce” or the factors that make Clarehouse effective and unique within the community.

Grounded Theory Research as Appropriate Methodology

In order to effectively answer the proposed question, I used a Classical Grounded Theory (CGT) methodology. Since the first usage of Grounded Theory in 1965 by Barney Glaser and Anselm Strauss in the *Awareness of Dying*, this qualitative methodology has developed three primary approaches or schools of thought (Stern, 2011). This study specifically utilizes the Glaserian (Classical) approach. Classic Grounded Theory is a qualitative research method that can often include quantitative research elements in regard to content analysis. CGT seeks to strategically compare one item of data to others gathered with the hope of gaining perspectives rather than verification of a specific theory.

The first distinguishing characteristic of Classical Grounded Theory is the identification of a general topic of interest to the researcher (Hoy, 2013). This means the research is not guided by a specific hypothesis. Rather, formal theories are developed based on the data that is collected or observed (Glaser and Strauss, 1967). This approach requires both an “inductive-deductive interplay” (McGhee et al, 2007). In other words, the researcher allows the patterns that begin to arise from the interviews to develop the direction of the study. For this study, our guiding topic was social model hospice and Clarehouse. In order to minimize researcher pre-conceived notions or biases, Glaser stresses the importance of not conducting a detailed literature review before the collection of the data (Glaser 1998; Hallberg 2010). The debate about literature is what helped to create the different schools of Grounded Theory (Stern, 2011; Hallberg, 2010). Ultimately, what is important is maintaining an open mind and reflexivity (Hallberg

2010; McGhee et al. 2007). In conjunction with Glaser, I did not conduct an in-depth literature review prior to my interviews. My readings prior to the interviews consisted primarily on topics regarding the methodology itself. Along with this, I took a course at Baylor University in end-of-life care and bereavement. While exposure to the literature of end-of-life care was relatively brief, the instruction I received in my Baylor course taught me to be aware of the emotions of the participants and how to listen to their stories and experiences.

Because of the nature of the study, approval from Baylor University's Institutional Review Board and the Board of Directors at Clarehouse was required. I prepared a formal proposal for Baylor's IRB, and the study was found to be exempt. After gaining exempt status from Baylor's IRB, I presented a formal research proposal. This was accepted by the Board of Directors at Clarehouse, and a memorandum of understanding was adopted.

A Classical Grounded Theory methodology is primarily interview based. Twenty three participants were interviewed for this study, the majority of whom were conducted on site at Clarehouse. However, some interviews took place via phone call, and one participant answered their questions via email. The length of interview time was variable. Some conversations lasted around 15 minutes while others lasted for 45 minutes. Interviews and observations took place over a duration of three weeks in the summer of 2019. After each interview, the responses were analyzed for patterns to help guide the questions that were asked in the next interview. No recording devices were used during conversations with participants. Detailed notes were taken of the interviews. Similar, to the practices of my thesis advisor, Dr. Hoy, I chose to not record conversations in order

to guarantee that I was actively present and listening. Further, showing the participants that I was available created an environment that facilitated deep, thoughtful discussion.

Participants were selected by the Education Director, Britni Smith and Executive Director, Kelley Scott, RN. Participants included current guests and family members of the home, family members of previous guests, staff, volunteers, members of the Board, members of the community, and other homes in the Omega Home Network. An initial email was sent asking about potential respondents' willingness to participate. Based on their response, a second email was sent to schedule an interview time.

The specific selection of individuals to participate in the study does not inhibit the reliability of the study; rather it strengthens it. The purpose of the study was to find common themes and patterns that contribute creating the "secret sauce" of Clarehouse. Therefore, it was imperative to talk with individuals who were able to thoughtfully reflect on why their Clarehouse experience was special or unique.

In order to gain a detailed and broad understanding of the contributing factors that make Clarehouse special, multiple comparison groups were interviewed. In accordance with Glaser and Strauss, "multiple comparison groups maximize credibility by helping the researcher to calculate where a given order of events or incidents is most likely to occur or not occur." (1965, p. 289-290). Further, multiple comparison groups quickly draw the researcher's attention to any major themes that are arising (Glaser & Strauss, 1965, p. 290). This aspect was fulfilled by interviewing present guests, present family members, family members of previous guests, current and past volunteers, current and past board members, and staff at other homes within the Omega Home Network.

After I conducted each interview, the method of constant comparison took place. Constant comparison is one of the distinguishing factors of CGT (Glaser & Strauss, 1967). Also known as coding, it is the process of finding patterns in the data due to the presence of repeated, “key-words.” Through the analysis and collection of data, common elements can be found that contribute to a greater understanding of Clarehouse. This process occurred until theoretical saturation was reached. Theoretical saturation means that new cases are not yielding any new information or categories (Hoy, 2013).

Along with using data from interviews, observations and physical documents were also used to develop the emerging themes. As best stated by Dr. Hoy, “...grounded theorists see all relevant information as potential data, treating field observations, written documents, artifacts, and the published work of other scholars as potentially important sources of data.” (2013 p. 18). The inclusion of observations is incorporated throughout the entirety of the study. After the data was collected and analyzed, research into the existing literature was the next step. Throughout this paper, I intentionally integrated the existing literature with my own observations and data. This allows the literature review to become additional data to be analyzed, carrying the same amount of weight as the other data collected (Hoy, 2013).

Throughout the observations collected, distinct patterns began to emerge. Regardless of the role of the participant (volunteer, staff, guest, family member, etc) similarities in their responses were consistent. As I began the process of constant data comparison and coding of the factors associated with Clarehouse and other social model hospice homes, five core components or “ingredients” of the secret sauce of Clarehouse began to emerge:

1. The physical attributes of the home
2. The volunteer base

3. Attention to detail
4. A structure of accountability
5. The practice of compassionate honesty

CHAPTER ONE

The Physical Attributes of Clarehouse

The physical attributes of Clarehouse are important because they highlight that the family and guests are not entering a medical facility such as a hospital or a nursing facility; rather, they are entering a home. Hospital environments that feel like home promote emotional comfort (Williams et al, 2008). Further, the hospital environment also plays a role in impacting the well-being, health, independence, and overall quality of life for elderly individuals at the end of life (Health et al, 2010). According to Respondent 2, “There is comfort that is found in the physical part of the building.”

The feeling of “home” was discussed by the majority of the individuals that were interviewed. This major theme is part of the foundation and purpose of Clarehouse. According to the mission statement of Clarehouse, “Clarehouse provides *a loving home*, quality end-of-life care and access to hospice services to people in need.” (Clarehouse.org).

Respondent 7, a family member, stated, “...It felt like home, there was a lot to do.” Along with this, the non-institutional environment felt like “Big-Cedar Lodge.” Respondent 9 discussed, “The first time you walk in, it feels like a very large home...it is important it feels like home because it provides comfort.” Respondent 8 stated, “It is important it feels like home because you want to feel comfortable going through this passage of life.” The feeling of home as discussed by the respondent and the purpose of Clarehouse highlights a causal relationship between a home-environment and positive feelings. Williams, et al. (2008) and Health, et al. (2010) emphasize that improvements in

physical and mental well-being in patients and family can be due small, specific considerations in the hospital setting.

Thus the question arises: How does Clarehouse facilitate the feeling of home in a physical space using physical components? In combination with the feelings of community fostered by the staff and volunteers, physical attributes such as privacy, proximity to nature, a place to gather, and small number of guests allowed at each time promotes a tangible feeling of being at home for both the guests, family, and friends.

Privacy

A major component that contributes to the defining characteristics of Clarehouse was the element of privacy. Clarehouse along with many other homes throughout the Omega Home Network (Journey Home, Abode Home, Sarah House, etc) specifically design their space to allow guests to have their own rooms. By emphasizing the guest and the guest's family, Clarehouse is able to create an environment of intentionality and individuality.

Respondent nine emphasized the intimacy and each individual having their own room. They discussed how a completely private setting with no other individuals helped to create feelings of ownership. Respondent 13 discussed the physical appearance, "They emphasize the architecture and privacy...vast difference between a hospital." Respondent 14 stated, "[Clarehouse] seeks to create an environment that is specifically for them [guests and family]...The environment matters." For example, Clarehouse utilizes individual thermostats and dimmers to create an environment that nurtures people (Respondent 14).

In one article, Brereton, et al (2012) seeks to understand the factors of what makes something a "home" in a hospital environment. They identify four key physical factors.

These include: “privacy as needed; proximity (physically and emotionally to loved ones, home, and nature; satisfaction with the physical environments; and deficiencies in the physical environments” (p. 981). Through their integrative review of ten articles, Brereton discusses how each of these factors are associated with positive attributes (Brereton et. al, 2012). In conjunction with Brereton, another study conducted by J. Rowlands, et al (2008) uses several semi-structured interviews to highlight major thematic elements. The elements are: staff behavior, the immediate environment, single vs multi-bedded rooms and contact with the environment.

In regards to patient privacy in the form of single vs. multi-bed rooms there exists a large debate within scientific literature. According to some, multi-bed rooms reduce patient isolation, loneliness, and depression (Rowlands et. al. 2008). Also, if there is not enough staff to accommodate the number of patients per room it becomes difficult to provide adequate care (Jolly, 2005). Further, some patients who are terminally ill do not prefer single rooms (Kirk, 2002).

While each statement above is valid and warrants careful consideration when creating an intentional space, Clarehouse has effectively addressed each issue as displayed throughout the consolidation of data gathered. Clarehouse is able to provide single rooms for guests without the fear of inadequate care being provided due to the size of the facility. By limiting the space to ten rooms, it ensures that the staff are able to properly give attention where attention is required. Along with this, as a patient becomes more ill they begin to prefer single rooms (Rowlands, et. al, 2008). Therefore, those who are actively dying along with their family members might find more comfort in individual spaces.

A Place to Gather

Along with having a space of privacy, creating specific settings for families to gather outside of the guest's room or interact with other families was indicated as being an important factor for caregivers and their time at Clarehouse.

Clarehouse features multiple spaces that can facilitate communication. On the second floor is a large, open room. Surrounded by windows, this room has small couches, chairs, and tables. On the first floor, there is a separate room with a door that can be closed for families to watch television and be by themselves. Following this are two sitting areas outside of the rooms with one couch and a few upholstered chairs. Lastly, the small, intimate dining room is open complete with a large, wooden dining table surrounded by artwork and an open view into the kitchen. In comparison, another home was described as having a "great room and kitchen as place of welcome for families." Another respondent discussed the physical attributes their facility, "It maintains a big, spacious kitchen...the kitchen is the most important."

Respondent 8, stated "The kids, grandkids, grandma were able to come. They played the piano and the family gathered." Respondent 16 observed families interacting with other families as part of the Clarehouse experience. "It impacted their journey, sitting and crying together." Respondent 19 stated, "The kitchen is the most important. It is where the most conversation happens." It represents the home of the person you loved. According to Respondent 2, Clarehouse was able to provide a space for her and her family: "Having time not to just spend with her, but spending time with gathered family in a designated space... Never got the feeling that you weren't welcome."

In order to properly fulfill the goals of Clarehouse of providing care both for the family and the guest, it is necessary to provide a space for families to solely be families and no longer the caregivers. One study found that family members ranked privacy statistically higher than patients (Heyland et. al, 2006). This seems to highlight the necessity of families requiring a space for private discussion and comfort from relatives (Heyland et. al. 2006). In another article, Evans, et al (2006) supports Heyland, et al (2006) view by stating,

“Having family present was important to many patients, and the small building with a central area for families made caregivers feel welcome. This facility design also encouraged camaraderie among members of different families and between caregivers and other patients.” (Evans et. al, 2006, p.107).

The data gathered throughout this study strongly coincides with the literature. In order to treat both the guest and the family, accommodations must be made that emphasize the importance of each individual. Sharing with family members or others in the same situation brings a more direct acceptance of upcoming death (Hinton, 1999).

Proximity to Nature

The proximity to nature or the emphasis on a naturalistic setting was frequently commented upon by caregivers of previous guests. Clarehouse was originally built at a distance from heavily populated areas. Expanding urbanization has resulted in new apartment complexes, hotels, and shopping centers very close to the facility. Regardless, the gardens of Clarehouse still aid in creating a feeling of seclusion and isolation away from the rest of the city.

Other homes throughout the Omega Home Network also maintain gardens and naturalistic, rustic environments. For example, when discussing the physical attributes of another home one respondent stated, “Each private room looks out onto green surroundings and is bright and beautiful.” According to another respondent, their facility is located on one-acre of land and was described as “peaceful” and “soothing”. Another home in the Omega Home Network includes large windows in each room allowing guests an easy view of the outdoors (Respondent 19).

When asked specifically about Clarehouse, many were quick to discuss the environment. Respondent 22 stated, “The physical attributes seek to create a sense of awe and wonder.” Respondent 5 had a cousin at Clarehouse and described it as “nice” and an “oasis”. Respondent 8 discussed the importance of maintaining the structure: “Making it feel like home by making it look more natural in a country setting. It is peaceful, and people appreciate the place.” They seek to keep it looking rustic and country. Respondent 10 stated, “I would sometimes go outside and walk the chapel garden—it was peaceful.” Respondent 13 highlighted the many ways that allow a family to grieve including: the butterfly release, the labyrinth, and the memorial rocks outside.

The proximity to nature and its positive benefits is supported by numerous studies. While research is still early, proximity and access to the outdoors has a correlation with satisfying psychological, emotional, and spiritual needs (Williams, 2004). Evidence of this is displayed throughout numerous historical healing sights (Williams, 2004). Significant research has been done that states hospital gardens and access to the outdoors elicit significant recovery from stress (Ulrich, 2004). Nature is positively correlated with reducing physical symptoms such as blood pressure and heart activity (Ulrich, 2004).

Brereton, et al (2012) asserts in hospital planning, it is important provide access or views of nature or outdoor spaces. Lastly, Rowlands, et al. (2008) found that individuals prefer having access to an environment with natural scenes or a view of the outside.

Small Structure

The number of available rooms and beds is also an important feature that distinguishes a home implementing social model hospice from an in-patient hospice program, a hospital, or a nursing facility. The smallness of the facility contributes to the attention to detail and intentional action that participants recognize when discussing the key attributes of Clarehouse.

Clarehouse began their program with only three available beds and then expanded to serving up to ten guests. Serving a small number of guests is a common theme shared by many of the interviewed homes in the Omega Home Network. Francis House has two homes. Each home is able to care for eight guests at a time. Abode Home is a three-bed home. Journey Home has six available rooms. Sarah House has eight rooms.

CHAPTER TWO

Volunteer Base

The volunteer base at Clarehouse is an important factor in defining the Clarehouse experience. Volunteers facilitate hospitality, intentionality, and service. As a member of the Omega Home Network, one of the key goals includes providing community-based care (Clarehouse.org). For Clarehouse, this criterion is partly fulfilled through the incorporation of their volunteer network. This section will discuss the size and character of volunteer base within Clarehouse along with a comparison to other homes throughout the Omega Home Network.

Number of Volunteers

Within the homes interviewed for this project, the number of volunteers each home utilizes varies greatly. Some facilities emphasize volunteerism while others do not. Currently, Clarehouse has around 200 volunteers led by a staffed, professional volunteer coordinator. Comparatively, Respondent 11, a staff member of another SMH home, states their home has around 32 volunteers. However, they did recently hire a volunteer coordinator. Respondent 19, reports that they “initially had a large volunteer base, but now it is relatively small... after moving into their new location the volunteer mentality shifted.” Their volunteers would always be welcomed in the house, but would not necessarily be welcomed in the rooms (Respondent 19). Respondent 19 further highlighted difficulties they had with a few volunteers who were motivated by religious goals and conversion. Respondent 20 states that they have around 50-60 active volunteers. Along with this, there is a volunteer coordinator on staff. Large, well-

established homes have a large volunteer base. Respondent 22 states, “We have over 400 volunteers who are active as gardeners, house volunteers, maintenance, and office.” The large volunteer base stems from being well-established within the community.

At this time, claims of causation—volunteers lead to a better experience—cannot be made. However, the data seems to highlight an association between the number of volunteers and the perceived involvement of the home within the community. The volunteer is able to bring in the outside world—life, news, etc. “They are able to hold the dying person in community.” (McKee et. al., 2010).

History of Volunteers

In regards to hospice care outside the realm of social model hospice, there has been a growing reliance and emphasis on volunteers. In a study conducted in 1999, researchers found that very few families had assistance from volunteers (Emanuel et al, 1999). Since then, there has been a rise in the number of volunteers due to financial, emotional, and physical benefits (Morris et al, 2013; Claxton et al, 2007). Similarly, homes practicing social model hospice, seem to maintain varying attitudes on the importance of volunteers. The mindset within SMH realm mirrors the progression and change of the perception of volunteers in “typical” hospice care.

Cost Saving Benefits

Clarehouse is a non-profit home and does not require monetary reimbursement for the care provided for the guests. Clarehouse serves everyone. Individuals who volunteer at Clarehouse are not paid for their services. According to a study conducted in 2005, volunteers may provide financial stability for end-of-life care organizations through the

provision of their organizational roles (Wilson, et al, 2005). In corroboration, an article discussing the impact of volunteerism in hospitals emphasizes that the substitution of volunteers for paid staff can potentially lower costs (Hotchkiss et al, 2014).

Characteristics of the Volunteers

The demographics of the individuals who serve at Clarehouse cover a broad spectrum. Along with this, each role that the volunteers take on is a direct reflection of their skills and abilities. For example, volunteers are not required to specifically interact with guests and families of the home. Rather, Clarehouse welcomes anyone who is willing to contribute anything. The age of the volunteer base ranges from 18-90 including students, young adults, the elderly. According to a narrative literature review conducted, the diversity of the staff and volunteers predicted a more diverse patient population (Morris et al., 2013). The large demographic of volunteers at Clarehouse may contribute in facilitating an environment that is welcoming to all. This solidifies the purpose of Clarehouse as being a community-based home because the entire community is welcome.

Clarehouse relies on volunteers in a multitude of ways. This includes: managing the gardens, the home, the front desk, the kitchen, laundry, fundraising, etc. Volunteers also contribute by sitting with guests and families if requested. Locally based physicians visit the home as volunteers and work with the hospice programs to help determine the best type of care for each individual. The volunteer program is run by a volunteer coordinator. The volunteer coordinator tries to align the goals of the volunteers with the goals of the home. This occurs via applications, interviews, scheduling, and communicating.

A key characteristic of the volunteer base at Clarehouse is maintaining a “paying it forward” mentality. While it is not required, many volunteers have had a personal

experience with Clarehouse. They personally know of someone who has stayed or been touched by Clarehouse. In a separate study conducted, researchers found that many volunteers were those who had an experience in end-of-life care or experienced the death of family member or friend. This highlights how volunteering in this field can be influenced by personal experience and desire (Claxton et al, 2007). Physician and humanitarian, Victoria Sweet said, “Whatever our current role, it was temporary. With time and the seasons, a host goes traveling and becomes a guest: a guest returns homes and becomes a host. That is what the word hospitality encodes.” (Sweet, 2013, p.196).

While the topic above discusses a “feed-forward” mentality, Clarehouse also cultivates feelings of reciprocity. Individuals are able to give back to Clarehouse through monetary and non-monetary donations. Much of the art displayed throughout Clarehouse are gifts from family members and friends. Respondent 7, a volunteer, discussed the meaning behind the painting of eagle hanging up in the conference room. Feelings of reciprocity, the ability to give back or mutually exchange, are accompanied by having greater feelings of efficacy (Howland et al, 2007). The inability to reciprocate can be viewed as a potential therapeutic barrier (Howland et al, 2007). In a separate study, researchers highlighted the importance of reciprocity between the worker-client relationship (Maidment, 2006).

Thus, the question arises, how does the volunteer base contribute to the Clarehouse experience? The presence of volunteers facilitates a culture and atmosphere of caring and compassion. Along with this, it provides a level of comfort to family members who may be battling with the idea of their loved ones dying. Volunteers represent individuals who strongly believe in the mission of the home. Individuals who make the intentional

decision to volunteer in an end-of-life care setting typically have more empathetic traits as compared to volunteers in a hospital setting (Egbert et al. 2003). Empathy, can best be defined as the ability to sense the emotions of others (Greater Good, 2019). Empathetic volunteers not only recognize the emotions of patients, they also are able to take the perspective of those they are caring for. They put themselves in the shoes of others. This trait allows for emotional, psychological, and physical treatment of the individual (Egbert et al. 2003). The tangible feeling of intentionality and kindness can be facilitated through volunteers.

The volunteer base also allows Clarehouse to feel like a home. Respondent 7 and Respondent 8 work on maintaining the grounds and the building. Respondent 12 serves at the front desk. Respondent 10 serves in the kitchen. Each role allows the family to relinquish control of caregiver and simply take the role as a grieving loved one. As best stated by Respondent 2, “By taking over the practical part for the family, it allows them to spend time with their loved one.” In a separate survey of family member’s satisfaction with volunteers, researchers found volunteers were able to provide emotional, informational, and social support (Claxton-Oldfield et. al, 2010). The accessibility and availability of the volunteer base also helps to facilitate an atmosphere of peace and understanding. According to Respondent 10, “Clarehouse felt like family... you don’t want or need for anything...When you walk in [they] wanted to hug you”. Respondent 10 is describing the “front door experience”. The minute that a family member or guest is brought through the door, they are greeted with a smiling face in a warm, welcoming environment. According to Respondent 2, the walk through the front door and the tour throughout Clarehouse are pivotal moments.

While we have established the importance of volunteers, the job of finding and maintaining volunteers is different. The ability to find new, suitable volunteers is a large organizational barrier to maintaining and increasing the volunteer population (Vanderstichelen et al, 2018). According to respondent 11, they did not have the manpower to take care of the home and actively search for volunteers. This problem does not necessarily have a quick answer or a quick fix. Clarehouse recruits volunteers via word-of-mouth, community outreach via large events and community conversation series, and social media. Respondent 12 discussed how Clarehouse reached out on Facebook for donations. Later after donating, the respondent returned to work as a volunteer. A study in England found that volunteers act as ambassadors to the community. They helped to promote services and fundraise (Morris SM et. al. 2015). An initial group of volunteers may be able to facilitate a chain reaction. Volunteers are able to fulfill roles that family, friends, and even staff cannot meet. As best highlighted in study conducted in Uganda, the community volunteer program acts as a ‘bridge to the hospice’ (Jack B. et al, 2011).

The utilization of volunteers is an important aspect to also highlight. With an abundance of volunteers, it is important to ensure the volunteers are not wasting their time and energy on tasks. For example, according to Respondent 17 emphasized “The utilization of a volunteer requires coordination, making sure their time is valued, and knowing their volunteers.” Along with this, it is important to understand that volunteers do not have to solely be used in the rooms interacting with the guests and families. Volunteers can be used in any medium. The importance of the volunteer is to be there (Claxton-Oldfield et al, 2007; McKee M. et al, 2010). Further the perceived presence of volunteers also has benefits. The number and sources available to provide assistance to a

patient correlates with an increase in patient's feelings of personal control (Williams et al, 2008). It is the presence of the volunteers that contribute to creating an atmosphere of giving, life, and peace. Regardless of where they are on the grounds, the volunteers are a pillar of creating the feeling of Clarehouse.

CHAPTER THREE

Intentional Action

The attention to detail, recognition of the little moments, is another important facet of the “secret sauce” of Clarehouse. Throughout conversations with staff, volunteers, family members, and guests each mentioned attention to detail. In the case of Clarehouse, what does attention to detail mean? Hospitals and nursing homes each address numerous factors: cleanliness, medication, patient history. What is the difference between the details found at Clarehouse as compared to those in an institutional setting? As best stated by Francis W. Peabody, M.D.,

“The good physician knows his patients through and through, and his knowledge is bought dearly. Time, sympathy, and understanding must be lavishly dispensed, but the reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine...for the secret of the care of the patient is in caring for the patient.” (2015, p. 1868)

While maintaining the goals of social model hospice Clarehouse pays special attention to the details of hospitality.

Attention to Detail

We have discussed how the architecture and setting of Clarehouse tends to create a home-like environment. Yet, it is important to remember that feelings of home are also cultivated by attitudes of the individuals inside. Welcoming and hospitable environments are created by multiple factors cohesively working together. This section will highlight the act of creating a personal, individualized environment.

The details of hospitality were alluded to throughout various statements. According to Respondent 2, “it is the tiny things...”. Respondent 6 says, “...finding out what they like

and rolling with it.” Respondent 9 stated, “Attention to details sets them [Clarehouse] apart... it is what makes it work”. Dignity and autonomy are major factors that provide emotional comfort for the dying individual (Williams & Irurita, 2004; Gott et al, 2004). Along with this familiarity, autonomy, and security are associated with the concept of home (Gott et al, 2004). In order to better understand how hospitality and feelings of dignity and autonomy coincide, we must establish the definitions of dignity and autonomy. Dignity is defined as the “quality or state of being worthy, honored, or esteemed” (Webster Dictionary). Comparatively, autonomy is defined as “self-directing freedom and especially moral independence” (Webster Dictionary). Feelings of value and control are personal ideas held by the individual, yet they can easily be influenced by the actions of others. Clarehouse functions well because they have discovered that their actions in creating a home-like environment can directly impact the mental and emotional state of their guests.

The details of hospitality cover a broad spectrum. In Clarehouse, this is seen as: ensuring that the guests favorite type of food is always available, allowing pets to stay in house, allowing family members to spend the night, 24/7 care, etc. In the dignity-conserving care model, the themes of living in the moment, not worrying about the future, and maintaining normalcy were identified as positively influencing perceptions of dignity (Chochinov, 2002). The responses from participants in the study also highlight this. For example, Respondent 5, a past guest at Clarehouse, fondly reflected on the large amounts of chocolate that were always available for her. Respondent #8 recalls Clarehouse asking their loved one what type of food was their favorite—the response was strawberry ice cream. From that moment onward, strawberry ice cream was continually

in stock for that individual. Respondent 3 recalls always bringing one guest a glass of whiskey with a little bit of water every night. Respondent 13 discusses bringing coffee and vodka to a guest. The concept of autonomy contains the ideas of self-determination, independence, and productivity (Murata, 2003). Typically, the people who find themselves at Clarehouse have lost independence and productivity. Therefore, the importance of allowing guests to pick their meals, make random requests, and choose their own schedule allows them to practice the important aspect of self-determination. In a separate study, researchers found that the type of food offered, the choice, and the manner influenced patient's perceptions of comfort (William et al, 2008).

Further examples of intentional action creating a caring environment can extend past providing food. Respondent #3 discusses "pillow therapy". While the rearrangement of pillows to a more comfortable position may seem minimal, it ultimately plays a large role in completing the mission of Clarehouse of devoted care. Respondent 10 reflected upon the staff of Clarehouse rubbing lotion on their spouse in the evening. In an article evaluating the quality of dying and death, addressing the whole person includes allowing dying patients to laugh, smile, be touched, hugged, and finding meaning and purpose (Patrick, et al, 2001). Respondent 5 conducted the entire interview with the company of her friends and pet dog. By attributing importance to the things that guests value, the staff address the personhood and value of the individual (Chochinov, 2002). Further, they are able to establish a connection and develop an empathetic and therapeutic relationship (Chochinov, 2002). Clarehouse allowing pets shows that they value their inhabitants. Likewise, research shows that visiting patients deem animals as important (Williams, et al, 2008).

Polimeni and Moore (2002) studied the experiences of women in a hospital, finding that real and perceived lack of control had a negative impact on the participants. However, those who perceived higher control experienced more satisfaction with their hospital stay. The provision of personal objects and individualized meals distinguishes Clarehouse as a home rather than a hospital. Being attuned to the personal needs of guests and accompanying family members and friends highlights the purpose of the organization.

Clarehouse also intentionally cares for the well-being of the family. Clarehouse allows families to take a step back in their role as caregiver and assume the role of grieving loved one. Multiple respondents discussed having the ability to spend the night in a comfortable setting. Respondent 5, a previous guest, specifically mentioned Clarehouse allowing families to stay overnight. Respondent 10, a family member of a previous guest, discussed how she was able to push the day bed near their spouse's bed to sleep near them. The ability to be close and intimate with their significant other helped to create a loving memory in the midst of a difficult moment. Each respondent reflected upon the stays in a soft, peaceful, and calm tones.

Respondent 8 highlighted the importance of the candy dishes. The candy dishes outside of the room represented a treat for them, indicating how important it was to have something small and sweet after sitting for hours. The respondent described the candy as representing a reward after the end of long, emotionally-wearing visits. Kellehear et al (2009) found how non-refrigerated food such as chocolates, jellies, hard sweets, and mints helped to create a feeling of a "home away from home" (p. 151). The creation of a

home away from home by the patient and the family help to create sense of individuality further, facilitating both dignity and autonomy.

Respondent 21, reflected how a family donated clocks to each room because it was so easy to lose track of time. Comparatively, interviews of terminally ill patients, patients have indicated the importance of being able to see a clock (Veatch & Veatch, 1994; Brereton et. al, 2012). Clarehouse hears the concerns of those who stay, and the team actively tries to adapt to their needs. Care is seen in the details of candy dishes and clocks. Not only do they enable feelings of autonomy with the guests, but they also seek ways to keep the family involved. We cannot disregard familial involvement in the care of guests and patients. Dignity is found in the midst of high-quality, relationship-based care (Potter, 2008). Giloth (1990) found by actively facilitating ways in which the family and the patient feel involved security and satisfaction are produced. In each of these instances, Clarehouse provided something unique. These unique actions are the memories that families recall when reflecting upon their stay.

Details of hospitality play a direct role in facilitating an environment of intentionality, empathy, and compassion. By continually going above the “norm” of caregiving as displayed by hospitals and nursing homes, Clarehouse along with other social model hospice homes are able to distinguish themselves as something different. According to respondent 13, “Everyone has different care and a different backstory.” In regards to the type of care respondent 14 states, “We are not making donuts.” This means that each guest and family is unique. By focusing on individualized care, it allows both guests and family members to find comfort in times of distress and anxiety. Families are able to rest and find greater peace in knowing their loved ones are being loved. In order to promote

dignity and the essence of medicine, the behaviors of the care-team must be founded upon small acts of kindness (Chochinov, 2007). Evans et al (2006) found that the attitudes of caregivers that emphasized that small acts of kindness made a large difference in transitions from home hospices to inpatient facilities. Respondent 14 states that attention to details is a method of respecting the dignity of the dying and maintaining a sense of self. Along with this, Clarehouse refers to patients as guests. This intentionality creates attitudes of self-respect.

CHAPTER FOUR

Accountability Structure

While we have discussed the importance of the volunteer base, we cannot disregard the value of the staff and board. Inadequate provision of palliative care can largely be due to organizational and cultural problems between the board, staff, and volunteers (Neergaard et al. 2008). During interviews, many individuals responded that the administration plays a hand in creating the Clarehouse environment. I sought to better understand how the attitude of the leadership at Clarehouse impacts the inner-workings of the home? This section will analyze the impact of the characteristics and actions by the board, staff, and executive director in creating a structure based upon accountability and value—another aspect of the “secret sauce of Clarehouse”.

Roles and Responsibilities

Several senior staff members exist at Clarehouse. The Clinical Manager manages the guest care and staffing while the Support Services Director coordinates guest, family, and staff support. The Education Director coordinates community, clinical, and social model hospice education. The Administrative Director provides home and campus management, human resources, and administrative support. The Development Administrator and Donor Relations Manager coordinate fundraising programs and communications. Finally, the Executive Director, oversees the management of Clarehouse and is responsible to the board for overall implementation of the Clarehouse mission. Each role is vital to the functioning of the home.

Each home within the Omega Home Network varies slightly with their staffing due to differing needs. Clarehouse has more administrative roles as compared to some other homes. This is due to the size, establishment in the community, and orientation towards being a home that emphasizes education and teaching. Some common denominators that are essential for a successful team include: set tasks, objectives, individual roles, and leadership norms (Hill, 1998; Handy, 1986).

Regardless of the staffing positions, the attitudes maintained by the administrative staff create an atmosphere based on care and intentionality. When there is a lack of respect between professionals, patients begin to doubt and have feelings of insecurity with the type of care they are receiving (Neergaard et al, 2008). A lack of understanding in the roles and responsibilities of the others within a palliative care team may result in a “form of gate-keeping” with appropriate care (Bliss et al, 2000 p. 286). The mission of Clarehouse includes educating everyone within the establishment on the importance of each role within the care team. The relationship between understanding and respect creates a unique environment. According to one respondent, “Grace is a state of compassion where someone feels comfortable enough to receive. The goal of Clarehouse is to facilitate an environment of grace.” The attitudes found throughout Clarehouse are oriented towards the bettering the quality of life for both the guest and the family.

Accountability of Staff

When discussing important qualities of the individuals working at Clarehouse, the lack of an institutional mindset was often cited as being a necessary qualification. People do have specific jobs; however, if there is a problem, regardless of hierarchy, everyone working within the home is quick to respond. The division of roles at Clarehouse is

viewed differently than traditional healthcare organizations. Being on staff at Clarehouse often means transcending “typical” job responsibilities. The employment of individuals who think differently and dynamically shifts the atmosphere from institution to home. Respondent 1, a staff member, stated, “Being on staff is like working in a family...The intent to make people feel like family happens at every level...the [administrative] staff are actively engaging because they care.” The feeling of being a part of a family is an aspect of the “secret sauce” of Clarehouse. Factors such as personal acquaintance break down prejudices and disrespect causing better cooperation (Neergaard et al, 2010). Respondent 2 discussed, “...sometimes the family doesn’t want to talk to the care staff, but they will reach out to administration...” it is about maintaining a perspective of “team work”. This supports earlier studies that found that patients feel more secure when they perceive that assistance was available to them (Williams et al, 2008). Respondent 3 states, “It [Clarehouse] flows as a team...The administration is always willing to come down.” Along with this, Respondent 6 said, “It looks and functions like a family...we look after each other.” One study discussed the notion that it is unrealistic to expect nurses to provide holistic care for their patients because of the levels of involvement it requires (Barthow, 1997). In order to provide the holistic care that many patients are looking for it is important to support the caregivers. The mentality of the staff, volunteers, and board at Clarehouse understand that it takes a team. Neergaard and colleagues (2008) found that bereaved relatives’ experience with palliative care depended on the shared care of the professionals. Based upon a qualitative group interview, the factors that contributed to the perceived palliative care experience included professional

responsibility, inter-professional culture, and inter-professional communication (Neergaard et al. 2008).

The creation of a professional culture that resembles a family is felt by the individuals staying at Clarehouse. Respondent 9 says, “People always seek to help.” Respondent 14, an individual on administration at Clarehouse, emphasized that one of the important qualities when looking for staff is the “ability to respond to where people are”. Respondent #12 discussed the beauty of “everyone stopping at line-up.” When an individual dies at Clarehouse, everyone present in the home lines up and creates a path as the individual and their family are escorted out in silence. The notion that the staff of Clarehouse functions as a family unit rather than in an institutional model emphasizes a structure of accountability. Traditionally, hospitals maintain a hierarchical culture with a top-down organizational structure (Hill, 1998). In comparison, hospices have a multi-professional approach based upon equality and a “flatter organizational structure” (Hill, 1998 p.220). This distinction is a factor in creating the difference between Clarehouse and nursing home or hospital. Improved cooperation requires a willingness to be “equal team partners” with respect and knowledge of each other’s strengths and competencies (Neergaard et al. 2010 p.1076).

The treatment of the staff and the volunteers creates a ripple effect in the type care given. Respondent 14 states, “We are as kind to each other as we are the guests... the culture of Clarehouse flows outside our doors.” Respondent 10 answered, “People who donate, staff, and facility is why it [Clarehouse] is working. Respondent 17, a current board member, highlighted the importance of volunteer appreciation.

Vanderstichelen and colleagues (2018) found that recruitment of suitable new volunteers was the most cited organizational barrier to maintaining a volunteer program. Volunteers may feel rejected when their “need for meaning and belonging to the hospice” is not satisfied (Morris et al, 2013). The people who work and volunteer at Clarehouse seem to understand that the work they are doing is important and necessary. Whether directly treating guests, fundraising, or mowing the lawn there is a common understanding that each job is vital and necessary. Trust and mutual respect are necessary prerequisites for successful cooperation (Neergaard et al. 2010). When individuals feel that their own dignity is respected, they are more likely to provide care that preserves the dignity of their patients (Potter, 2008; Brereton, 2012).

The lack of hierarchy in the importance of jobs facilitates the type of care each guests receives. Each guest receives equal care regardless of socio-economic status, age, background, or connection to the home. All homes within the Omega Home Network practicing social model hospice are non-profit—community based care provided by the community. According to Respondent #8, regardless of their association with the home, it still took three days for their loved one to get in, and “that’s the way it should be.” Respondent 17 emphasized the practice of equal treatment. Respondent 11 states, “We don’t look at income or need...treatment of everyone we serve is the same.” And “[It is] the process of ensuring adequate care. There is no poor quality care.” Attitudes are important, and they should be based on kindness and respect (Chochinov, 2007). The type of attitudes others demonstrate with patients has an impact on their perceived social dignity (Chochinov, 2002). Respondent 3 described it as a “humanitarian concept” and “more personal”. Cantor (1989) highlighted that in order to better treat the elderly and

dying within our community, a partnership between the family and community must be made. Along with this, the community must take an active role in providing service (Cantor, 1989). The community-based care that Clarehouse along with other homes practicing social model hospice are an important answer to the problems presented throughout this article almost 30 years ago.

Characteristics of Staff

The quality of the administration and board is also emphasized by the longevity of the individuals in their positions. While there are exceptions, the people who work at Clarehouse are generally there for long periods of time. According to Respondent 7, “People contribute to Clarehouse. This includes the loving and caring staff and long-term volunteers.” Respondent #8 stated, “The staff stays for a long time because they enjoy the work in making people comfortable.” In an interview with another home, one respondent stated, “Being there long term creates the feeling of a family. You get to know each other.” Along with this, according to Respondent 3, “There is a self-screening mindset. You can tell pretty quickly if someone does not have the right mentality.”

Clarehouse is also unique because they have an inter-disciplinary team (IDT) composed of the nurses, volunteers, staff, and medical liaisons. The inter-disciplinary team is not itself unique to Clarehouse. Rather, holistic teams are a characterization of palliative care as a whole. The gathering of the team for meetings highlights that everyone—volunteer to executive director—plays a vital role in creating a positive experience for the guests and family members at Clarehouse. It creates an intentional space where people can feel heard and appreciated. There is an association between communication of health professionals and the caregiving team and the success of shared

care (Neergaard et al, 2008). This communication at Clarehouse is facilitated by a weekly meeting. Case conferences are credited with creating feelings of greater team appreciation along with reduced professional isolation between general practitioners and the palliative care team (Del Mar et al, 2005). While this study analyzed the relationship between the GPs and the palliative care team in a hospital setting, the observations they made can still be applied to the organizational structure of Clarehouse. The involvement of everyone is necessary to solving complex problems and making high quality decisions (Hill, 1998).

Not surprisingly, many individuals also discussed the valuable leadership of the founder and Executive Director, Kelley Scott. Respondent #1 stated, Kelley helps people feel comfortable.” Respondent 18 highlighted, “the whole idea was born out of Kelley.” Respondent 3 discussed how they learned from Kelley. In a study analyzing the bereaved relatives’ experiences with palliative care, researchers highlighted the importance having a coordinator for successful shared care (Neergaard et al. 2008; Neergaard et al, 2010). Clarehouse partners with local hospice groups and implements the directives given. This unique structure requires communication and coordination between Clarehouse and the hospices in order to provide adequate care. While the idea began with Kelley, Respondent 21 discussed the measures that Clarehouse has taken in order to avoid the “Founder’s Trap”. They stated, “In order to avoid an organization falling apart, succession planning and steps forward must be implemented or discussed... charismatic does not equal execution.” They discussed the nature of the “highly functional board” of Clarehouse. Many members of the board actively volunteer at Clarehouse. Along with this, they seek to make Clarehouse integral to the community. Barker (2000) found that

women displayed more qualities of transformational leadership than men had more qualities of transactional (Barker, 2000). Both types are necessary for the success of an organization; however, transformational leadership within the field of hospice and palliative care units is important in creating relationships (Barker, 2000).

Staff Structure within the Omega Home Network

Similar to characteristics found in the staff at Clarehouse, other homes throughout the Omega Home Network emphasized the importance of teamwork and the “feel of a family”. Along with this, they also discussed the importance of compassion and flexibility. For example, one home stated their staff and volunteers must “feel called to this ministry”, which means that they have compassion and are dedicated to the comfort of others. They must be upbeat, healthy, and willing to go through training and background checks. Another home highlighted the importance of their staff having dealt with death and dying prior. They also emphasized that having a “nursing-home mentality” does not work—“you either get it or you don’t.” In comparison, another home stated, “good intentions do not necessarily mean it is a good fit. They must be able to work as a team.” Clarehouse functions well because they have cultivated a staff that maintains mentalities based upon the organizations foundations.

CHAPTER FIVE

Compassionate Honesty

Clarehouse is also characterized by its mission towards continual education and compassionate honesty. Guests, family members, the surrounding Tulsa community, and homes within the Omega Home Network strive towards facilitating informative, honest conversations about the dying process. In an analysis discussing the preferences of prognostication between parents, children, and physicians Mack and colleagues (2016) found that majority of parents felt that having a numerical understanding of the prognosis was extremely important. Even when parents found the information upsetting, they still viewed the information as important in decision making (Mack et al, 2016). Throughout this study, compassion and sensitive care was seen in the physician's willingness to inform and deliver detailed information (Mack et al, 2016). While this study analyzed pediatric patients, the information gained is still valuable and applicable to adults. Regardless of the circumstances, families rely on clarity and the discernment of caregivers. Further, communication is not only necessary for the patient but is also equally important for the family members (Keeley, 2016). The education program at Clarehouse is multi-faceted. The honesty exhibited through education, allows the team at Clarehouse to facilitate feelings of kindness and intentionality. Clarehouse recognizes the importance of being informed. The skills necessary to navigate sensitive topics are continually developing and changing (Canellos, 2000). Clarehouse seems to adapt with changing circumstances.

Observations of Open Communication

It is important to understand that the honesty displayed throughout Clarehouse is not harsh or forced. Most hospice programs contain an educational aspect. Therefore, it is important to highlight the differences and relationship between the two. The characterization of conversations is best seen through the responses of those interviewed.

Respondent 1 reflected upon their time at the hospital saying, “We had no idea she was even dying...” And “Clarehouse explained everything properly... The staff helped with understanding.” Respondent 3 described a previous encounter with a guest and their comment, “I’ve just never died before.” While brief, this comment conveys the complexities of dying. It is individual, confusing, and potentially frightening.

One of the goals of Clarehouse is to alleviate anxiety and fear by openly discussing what is to be expected. Respondent 5, a previous guest at Clarehouse, stated, “The doctors and nurses are kind and straightforward...honesty in caring.” The open communication and honesty regarding the patient’s condition showed her that she was cared for.

A common theme emerged that Clarehouse utilizes compassion and education to care for families and guests in the transition to death. Respondent 8, described how there is a common understanding when one is at Clarehouse. Individuals staying at Clarehouse met the requirements of either already being admitted to home hospice care or have a medically verified life expectancy. Therefore, many barriers in communication about end-of-life such as the fear that discussion about end-of-life care could cause harm or death and protecting physicians from uncomfortable situations (Curtis & Patrick, 1997) are innately avoided. While there are exceptions, most families enter Clarehouse in the open awareness context. Open awareness, as defined by Glaser and Strauss means that

both the care team and the patient know that the patient is dying (Glaser & Strauss, 1965). This is acknowledged through their actions (Glaser & Strauss, 1965). There are times when a patient is unwilling to hear about their state and this can result in difficulties. In a case study, one physician discussed the moral dilemmas present when a patient did not want to know her terminal status (Neff et al, 2002). In his reflection of the case, the physician emphasized that it is out of respect for the patient's autonomy that we are honest about their condition (Neff et al, 2002). The unique nature of Clarehouse, its physical attributes, the details, the staff all works together to gently bring reluctant guests and families into a state of awareness.

Though oncologists are generally aware of the necessity of delivering hard news in a compassionate and understanding manner, many have not had specific training in how to do this. However, it is not necessary for a single individual to address these issues alone; rather, hospice, palliative care teams, and physicians functioning together promote conversation (Loprinzi et al, 2010).

Clarehouse specifically trains their staff and volunteers to be equipped to talk with families and patients. Respondent 9 stated, "the staff was wonderful, they explained everything. They were open and honest and willing to answer." Along with this, they stated that the difference between Clarehouse and a nursing home. They described how they had to push for answers whereas "Clarehouse always kept us informed". Respondent 9 also addressed the importance of the "blue book". *Gone From My Sight-The Dying Experience*, is a short book with a blue cover that discusses the physical, emotional, and mental changes that accompany an individual in the active dying process. Respondent 9 reflected about how it told them what to expect and made them aware of the transitions of

the dying process. Respondent 12 stated that they were kept up to date and aware, told what to expect, and how to prepare for the next days. For Respondent 12, the understanding and purpose of Clarehouse came after the death of the loved one.

Throughout Ira Byock's, *Dying Well*, he emphasizes that dying patients need to be able to tell their loved ones four important things: I forgive you and please forgive me, thank you, I love you, and goodbye (1998). By keeping families and guests informed on the transitions, Clarehouse allows for individuals to address these points. Respondent 16 stated, they were alerted of coming death. Along with this, facilitating conversation helps to put people at ease, and Clarehouse's experience helped to pave the road. Respondent 14, a member of the administration stated, "We are not afraid to use language such as death, dying, and died." Respondent 14 discussed how they strive to be honest and upfront. However, it is not their job to "be in people's face" rather, "we will always offer information, but we will not stuff it down someone's throat...Clarehouse is here for the hard conversations."

Berry (2008) suggested using clear language in describing conditions helps to nurture and build relationships. Along with this, using euphemisms can result in confusion and perpetuates the idea that death is a taboo subject (Berry, 2008). Respondent 18 stated, "there was openness and acceptance of death". They also stated, "People want to do it right, but don't know how. Clarehouse provides a hope for a good death...They said here is the disease process, here is what you can expect, and here is how we can help you." They reflected how the idea of someone dying with you in charge is scary. Respondent 18 reflected upon the importance of education from the bedside.

Respondent 21 stated, “Clarehouse is about changing a mindset and shifting a frame based on education and reorientation.” Respondent 22 stated that the biggest question people have is, “Am I doing it right?” Families and caregivers are also suffering, and they need forewarning and guidance in order to grieve, grow, and heal (Bretscher, 2003). It is important for family members to have the opportunity to express that their family member may die (Heyland et al, 2006). The success of Clarehouse is seen in its ability to facilitate compassionate communication in vulnerable situations. Prognostic information is important to maintaining hope (Mack et al, 2016). While hope may not necessarily come directly from the prognostic information, it may stem from the caring relationship in which it was given (Mack & Smith, 2012). Further the reluctance to avoid talking about death typically stems from a place of wanting to prevent harm rather than actions of maleficence. (Loprinzi et al, 2000). However, perspectives of hope can be reframed based on the context of the individual (Loprinzi et al, 2000).

Contrastingly, Helft (2005) discussed the notion of “necessary collusion” or the act of avoiding or delaying discussions about life expectancy in order to address patient wishes and maintain hope. In response, one physician emphasizes that maintaining hope is an important aspect of care; however it is not the core principle (Loprinzi et al, 2010). It is important to be able to have conversations that include hope along with aids in helping to make practical, informed decisions (Loprinzi et al, 2010; Leighl et al, 2004).

While conducting interviews, I also had the opportunity to observe the interactions between the staff, volunteers, and guests. During one encounter, a guest was concerned about her issue with choking on food. The guest was visibly distressed and worried about her declining abilities. The medical liaison gently explained that difficulties in

swallowing and choking were normal and to be expected. Along with addressing the fears of the guest, the medical liaison provided helpful tips on how to more effectively swallow in order to help prevent the problem. In a separate scenario, the relative of a guest was very worried about their loved one not eating or drinking anything. I observed how the caregivers gently explained that a lack of appetite and not eating or drinking were to be expected. Along with this, forcing food and liquids into the guest would do more physical harm than good. The notion that water and food could be harmful is sometimes a hard idea to grasp, and the care team was open and willing to answer more questions about the topic. Research shows that giving patients and family members honest information may positively influence abilities to cope with an illness (Mack & Smith, 2012). Moreover, good staff communication is credited with reducing anxiety and improving outcomes (Chochinov, 2002; Rowlands, 2008)

The facet of teaching aids in creating an environment that is open and honest. Most hospice programs serve their patients by being a source of information regarding the next steps; however, Clarehouse works in partnership with the hospice program to strengthen the learning process. Clarehouse promotes a sense of availability and a willingness to be present. In a study analyzing caregivers experiences in transfers from home hospice to inpatient facilities, researchers found that families deeply appreciated open communication (Evans et al, 2006). Personalized care that was based upon established goals made the participants feel valued and affirmed (Evans et al, 2006). Personal levels of control are associated with increased provision of information (Williams et al, 2008). Answering questions, alleviating concerns, and giving attention to concerned family

members highlights that the guests who come to Clarehouse are valued and important—the secret sauce of Clarehouse.

The Presence of Medical Liaisons

Most homes within the Omega Home Network, homes practicing social model hospice, do not have physicians who routinely round on patients. The presence of volunteer physicians or medical liaisons is unique to Clarehouse. The purpose of the volunteer physician at Clarehouse is a result of two major factors: mission and location. Clarehouse made the decision to not expand/build another home, but rather to extend its services via education. Physicians are present at Clarehouse to better facilitate communication about death and dying within the medical community. The medical liaison's role includes offering information for guests and family members, working with hospice programs, and allowing people throughout the community to shadow. This includes: high-school students, under-graduate students, graduate students, medical students, and physicians.

Having a previous death experience or witnessing other people die is associated with greater acceptance of the finality of death (Hinton, 1999). The exposure that Clarehouse provides can directly influence future responses. Further, patients who had family or friends die were more likely to talk with their primary care physician about end-of-life care (Curtis, 2000). Along with this, Tulsa is a center for medicine in the state of Oklahoma. The presence of multiple medical programs, nursing programs, and hospitals allows for the community to handle complex diseases. As a result, when an individual who is dying from a complex disease/diagnosis is admitted to Clarehouse the medical liaison communicates exactly what is happening thus providing understanding to the

family. Respondent 10 stated, “The physician comes in and clearly explains everything that was going to happen.” Physicians who are unable to carry on a conversation in a thoughtful, empathetic manner are perceived as blunt and uncaring (Back & Arnold, 2006). Therefore, when discussing expectations and transitions thoughtful communication skills are required (Back & Arnold, 2006). The medical liaisons, LPNs, and volunteers are each equipped with the skills to engage the guests in growing their understanding.

The medical liaison along with the care team work in conjunction with the hospice and the patient’s general practitioner. They cannot prescribe medicine or treatment. However, they can listen to the concerns of the guest and take steps forward to help alleviate pain or other symptoms. Clarehouse helps to coordinate care. It is important to emphasize that the care given at any social model hospice home is anything that a family member (in theory) could provide to their loved one while at home. The presence of nurses and physicians is not a requirement. Clarehouse uses them primarily as an educational component. The ability to assess the quality of a death is based upon a person’s preferences were fulfilled (Patrick et al, 2008). The establishment of goals occurs through communication and observations (Patrick et al, 2008).

CHAPTER SIX

Study Limitations and Concluding Remarks

Study Limitations

In the collection of data, precautions were taken to reduce researcher bias and to ensure quality data analysis. Unfortunately, limitations are still present due to the nature and structure of the study. Because we began the study with an established understanding that Clarehouse was effective, the questions were structured to ask “how” rather than “whether and how”.

In many qualitative research studies, more than one researcher is present in both the collection of data and analysis. Known as *investigator triangulation*, Denscombe (2007) describes that having many people present can potentially limit bias through a series of checks and balances. Along with this, having multiple people engaged in the research process helps to facilitate novel ideas. The nature of end-of-life care conversations, which often become quite intimate, made a single interviewer seem to be a better choice for this study. However, throughout the interview process communication between the researcher and the mentors and the analysis of field notes, hopefully minimized bias present.

Along with this, Denscombe (2007) discusses the *interviewer effect*. The interviewer effect demonstrates that people respond differently to questions based upon the sex, age, and ethnic origin of the interviewer. Therefore, the data is unintentionally affected. It is possible that the respondents answers were formatted in a way to support the research design, or that some participants felt that they did not have the ability to discuss negative experiences at Clarehouse. While this limitation is inherently present, it is hoped that

interviewer effect was reduced because the interviewer was not a medical professional, member of a news or media team, nor had any direct connection to Clarehouse. Along with this, participants were first contacted by the Education Director at Clarehouse on their willingness to participate. Then, after a second confirmation by the interviewer, each participant heard an explanation of the interview process and the consent protocol which highlighted anonymity, with the goal of allowing open discussion of ideas and explanations.

Limitations also occurred in the method that interviews were conducted. The majority of the interviews took place in-person in Tulsa, Oklahoma at Clarehouse. However, for some participants, an in-person interview was not feasible. These interviews were conducted over the phone, and one interview was conducted via email. Overall, phone-call interviews were shorter than those completed in-person; however, the remarks and observations made by the participants still contributed to the developing themes and patterns.

At first glance, the sample size used throughout this study seems relatively small and divergent. It is important to emphasize that in a Classical Grounded Theory methodology, interviews only continue until theoretical saturation is reached. The variety of individuals interviewed, including volunteers, staff, board members, guests, family members of guests, and community members was done intentionally in order to gain a wider, more complete scope of the Clarehouse experience. Additionally, as stated in the introduction, the specific selection of individuals to participate in the study does not inhibit the reliability of the study, rather it strengthens it. The purpose of the study was to find common themes and patterns that contribute to the “secret sauce” of Clarehouse.

Therefore, it was imperative to talk with individuals who were able to thoughtfully reflect on why their Clarehouse experience was special or unique.

Concluding Remarks

Despite the limitations mentioned, it is hoped that the findings of this study may offer insight into ways to inspire current social model hospice programs. While the viability of some aspects of the social model hospice programs and the Omega Home Network are dependent upon specific state governments, certain factors and qualities discussed throughout this paper can easily be applied or analyzed to existing homes. While grounded theory studies are not thought to be generalizable, the patterns highlighted throughout this study are not limited to Clarehouse.

It is important to recognize that each of the patterns described: compassionate honesty, physical attributes, volunteer base, staff structure, and attention to details all must work together in order to create an environment that is characterized by hospitality, grace, and compassion. Each chapter has explored one of the identified “ingredients” to the “secret sauce” of Clarehouse. When one factor is weak, it negatively impacts the strength of the other aspects. Much like a recipe missing an ingredient or lacking the correct concentration, the overall flavor is affected. These concluding statements will summarize the main themes and offer further suggestions for continued research.

The physical attributes of the home play a distinct role in creating an atmosphere that feels like a home rather than nursing home or hospital. Based upon interviews and observations, specific elements within this umbrella category are privacy, a place to gather, a proximity to nature, and a small structure. Coinciding with the outward appearance of the home the characteristic of the staff in conjunction with the volunteer

base facilitate intentional, detail-oriented action along with compassionate honesty. Each factor generates a pay-it-forward mentality of kindness.

This study highlights five main themes. Based on interviews/conversations and observations collected, these elements were deemed important. However, this does not mean that these are the sole elements necessary for a “successful” home. Due to the relatively recent introduction of SMH to the literature, not much research has been completed on impact of this type of care. Further quantitative research can be done at Clarehouse to further validate the patterns that emerged. Along with this, a comparative analysis of the homes within the social model hospice network may be useful to gain greater understanding of the complexities of each home. Further research could provide more guidance with balanced findings to the Omega Home Network.

My introduction to social model hospice, Clarehouse, and end-of-life was rather unconventional. My introduction to the field did not begin with the death of a loved one, rather, my interest Medical Humanities prompted me to take a course in end-of-life care and bereavement at Baylor University. From that moment, a series of doors began to open that allowed me to pursue a qualitative study at Clarehouse in Tulsa, Oklahoma. Ultimately, my experience has taught me the importance of facilitating education and understanding on death, dying, and hospice. Organizations such as Clarehouse would not be able to exist or function without the aid of the greater surrounding community.

APPENDIX

APPENDIX

Semi Structured Interview Guide:

Guests of Clarehouse

- Will you take some time to describe to me how your experience at Clarehouse has been so far? In other words, how you have experienced it working for you?
- Why do you think this is working?
 - What makes that so? Tell me more about that
 - Are there some particular actions of staff or elements of your surroundings that make this a good option? What would make you recommend it or not recommend it to others?

Family Members

- What factors have contributed to the medical decisions you have chosen to make?
- Describe your experience at Clarehouse, how has it been working for you?
- What was your care plan like before Clarehouse, what role did you play?
 - How has Clarehouse helped you through this process?
- Why do you think this is working? What makes that so? Tell me more about that.
- Are there some particular actions of staff or elements of your surroundings that make this a good option? What would make you recommend it or not recommend it to others?

Staff/Volunteers

- Why did you choose to work at Clarehouse?
- What role do you play?
- What factors and experiences contribute to the Clarehouse experience?

Community

- Will you tell me a bit about what you know about Clarehouse?
- In your opinion what does the purpose of Clarehouse seem to be?
- If you had a relative or friend in need of its services, do you suspect you would recommend they utilize the services of Clarehouse? Why or why not?
- (If the respondent's responses have been generally positive): What would be the elements of Clarehouse's philosophy, mission, or program you think should be replicated in similar programs?

REFERENCES

- Autonomy. (2020). Autonomy [definition]. *Merriam Webster Online*. Retrieved October 23, 2019, from <https://www.merriam-webster.com/dictionary/autonomy>
- Back, A. L., & Arnold, R. M. (2006). Discussing prognosis: “How much do you want to know?” Talking to patients who are prepared for explicit information. *Journal of Clinical Oncology*, *24*(25), 4209–4213. <https://doi.org/10.1200/JCO.2006.06.007>
- Barker, L. (2000). Effective leadership within hospice and specialist palliative care units. *Journal of Management in Medicine*, *14*(5/6), 291–309. <https://doi.org/10.1108/02689230010362909>
- Barthow, C. (1997). Negotiating realistic and mutually sustaining nurse-patient relationships in palliative care. *International Journal of Nursing Practice*, *3*(4), 206–210. <https://doi.org/10.1111/j.1440-172X.1997.tb00103.x>
- Berry, S. R. (2008). Just say die. *Journal of Clinical Oncology*, *26*(1), 157–159. <https://doi.org/10.1200/JCO.2007.12.3224>
- Bliss, S. C., While, A. J. (2000). Interprofessional working in palliative care in the community: A review of the literature. *Journal of Interprofessional Care*, *14*(3), 281–290. <https://doi.org/10.1080/jic.14.3.281.290>
- Brereton, L., Gardiner, C., Gott, M., Ingleton, C., Barnes, S., & Carroll, C. (2012). The hospital environment for end of life care of older adults and their families: An integrative review. *Journal of Advanced Nursing*, *68*(5), 981–993. <https://doi.org/10.1111/j.1365-2648.2011.05900.x>
- Bretscher, M. (2003). Caring for dying patients: what is right? *Journal of Clinical Oncology*, *21*(90090), 3s–34. <https://doi.org/10.1200/JCO.2003.01.154>
- Byock, Ira. (1998). *Dying well: peace and possibilities at the end of life* (1 ed.). New York: Riverhead Books.
- Cantor, M. H. (1989). Social care: family and community support systems. *The Annals of the American Academy of Political and Social Science*, (503), 99–112.
- Chochinov, H. M. (2002). Dignity-conserving care—a new model for palliative care: helping the patient feel valued. *JAMA*, *287*(17), 2253–2260. <https://doi.org/10.1001/jama.287.17.2253>

- Chochinov, H. M. (2007). Dignity and the essence of medicine: The A, B, C, and D of dignity conserving care. *BMJ: British Medical Journal*, 335(7612), 184–187. <https://doi.org/10.1136/bmj.39244.650926.47>
- Claxton-Oldfield, S., & Claxton-Oldfield, J. (2007). The impact of volunteering in hospice palliative care. *American Journal of Hospice and Palliative Medicine*®. Retrieved from <https://journals-sagepub-com.ezproxy.baylor.edu/doi/abs/10.1177/1049909106298398>
- Claxton-Oldfield, S., Gosselin, N., Schmidt-Chamberlain, K., & Claxton-Oldfield, J. (2010). A survey of family members' satisfaction with the services provided by hospice palliative care volunteers. *American Journal of Hospice and Palliative Medicine*®, 27(3), 191–196. <https://doi.org/10.1177/1049909109350207>
- Curtis, J. R. (2000). Why don't patients and physicians talk about end-of-life care?: Barriers to communication for patients with acquired immunodeficiency syndrome and their primary care clinicians. *Archives of Internal Medicine*, 160(11), 1690–1696. <https://doi.org/10.1001/archinte.160.11.1690>
- Curtis, J. R., & Patrick, D. L. (1997). Barriers to communication about end-of-life care in AIDS patients. *Journal of General Internal Medicine*, 12(12), 736–741. <https://doi.org/10.1046/j.1525-1497.1997.07158.x>
- Del Mar, C., Mitchell, G., BurrIDGE, L., Kennedy, R., Weeden, K., O'Rourke, P., ... Clavarino, A. (2005). General practitioner, specialist providers case conferences in palliative care: Lessons learned from 56 case conferences. *Australian Family Physician*, 34(5), 389–92. <https://doi.org/10.2267/0300-8495.34.5.1795>
- Denscombe, M. (2007). *The good research guide for small-scale social research projects* (3rd ed.). Maidenhead: Open University Press.
- Egbert N and Parrott R. Empathy and social support for the terminally ill: implications for recruiting and retaining hospice and hospital volunteers. *Comm Stud* 2003; 54(1): 18–34
- Emanuel, E. J., Fairclough, D. L., Slutsman, J., Alpert, H., Baldwin, D., & Emanuel, L. L. (1999). Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *The New England Journal of Medicine; Boston*, 341(13), 956–963.
- Empathy. (2020) Empathy [definition]. *Greater Good*. Retrieved October 14, 2019, from <https://greatergood.berkeley.edu/topic/empathy/definition>
- Evans, W. G., Cutson, T. M., Steinhauser, K. E., & Tulsky, J. A. (2006). Is There No Place Like Home? Caregivers Recall Reasons for and Experience upon Transfer

- from home hospice to inpatient facilities. *Journal of Palliative Medicine*, 9(1), 100–110. <https://doi.org/10.1089/jpm.2006.9.100>
- Gawande, A. (2014). *Being mortal: Medicine and what matters in the end* (1 edition). New York: Metropolitan Books.
- George P. Canellos. (2000). The art of oncology-when the tumor is not the target. *Journal of Clinical Oncology*, 18(1), 3.
- Giloth, B. E. (1990). Promoting patient involvement: educational, organizational, and environmental strategies. *Patient Education and Counseling*, 15(1), 29–38. [https://doi.org/10.1016/0738-3991\(90\)90005-6](https://doi.org/10.1016/0738-3991(90)90005-6)
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying* (1 edition). New Brunswick, NJ: Aldine Transaction.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New Brunswick: Routledge.
- Gomes, B., Calanzani, N., Gysels, M., Hall, S., & Higginson, I. J. (2013). Heterogeneity and changes in preferences for dying at home: A systematic review. *BMC Palliative Care*, 12(1), 7. <https://doi.org/10.1186/1472-684X-12-7>
- Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. (2004). Older people's views about home as a place of care at the end of life. *Palliative Medicine*, 18(5), 460–467. <https://doi.org/10.1191/0269216304pm889oa>
- Grant, H. S., & Scott, K. K. (2015). An introduction and overview of social model hospice care: *Journal of Hospice & Palliative Nursing*, 17(5), 456–461. <https://doi.org/10.1097/NJH.0000000000000186>
- Hallberg, L. (2010). Some thoughts about the literature review in grounded theory studies. *International Journal of Qualitative Studies on Health and Well-Being*, 5(3), 5387. <https://doi.org/10.3402/qhw.v5i3.5387>
- Handy C (1986) *Understanding Organization*. Penguin, London
- Health H., Sturdy D. & Wilcock G. (2010) Improving quality of care for people with dementia in general hospitals. *Nursing Older People, Quality of Care Supplement*; Summer, 1-16
- Helft, P. R. (2005). Necessary collusion: prognostic communication with advanced cancer patients. *Journal of Clinical Oncology*, 23(13), 3146–3150. <https://doi.org/10.1200/JCO.2005.07.003>

- Heyland, D. K., Dodek, P., Rocker, G., Groll, D., Gafni, A., Pichora, D., ... Lam, M. (2006). What matters most in end-of-life care: Perceptions of seriously ill patients and their family members. *CMAJ: Canadian Medical Association Journal*, 174(5), 627–633. <https://doi.org/10.1503/cmaj.050626>
- Hill, A. (1998). Multiprofessional teamwork in hospital palliative care teams. *International Journal of Palliative Nursing*, 4(5), 214–221. <https://doi.org/10.12968/ijpn.1998.4.5.9099>
- Hinton, J. (1999). The progress of awareness and acceptance of dying assessed in cancer patients and their caring relatives. *Palliative Medicine*, 13(1), 19–35. <https://doi.org/10.1191/026921699672169546>
- Home. (n.d.). Retrieved April 27, 2019, from Clarehouse website: <https://www.clarehouse.org/>
- Hotchkiss, R. B., Unruh, L., & Fottler, M. D. (2014). The role, measurement, and impact of volunteerism in hospitals. *Nonprofit and Voluntary Sector Quarterly*, 43(6), 1111–1128. <https://doi.org/10.1177/0899764014549057>
- Howland, W. (2007). Therapeutic reciprocity. *American Journal Of Nursing*, 107, 15–15. Retrieved from https://baylor.primo.exlibrisgroup.com/discovery/fulldisplay?docid=wos000250797400006&context=PC&vid=01BUL_INST:BAYLOR&lang=en&search_scope=MyInst_and_CI&adaptor=Primo%20Central&tab=Everything&query=any,contains,Therapeutic%20reciprocity&offset=0
- Hoy, W. G. (2013). *Do funerals matter?* (1 edition). New York: Routledge.
- Jack, B. A., Kirton, J., Birakurataki, J., & Merriman, A. (2011). ‘A bridge to the hospice’: The impact of a community volunteer programme in Uganda. *Palliative Medicine*, 25(7), 706–715. <https://doi.org/10.1177/0269216310397566>
- Jolly, S. (2005). Single rooms and patient choice. *Nursing Standard*, 20(9), 41.
- Jones, S. (2011). *The medicine we carry: A portrait of social-model hospice care* (Ph.D., Pacifica Graduate Institute). Retrieved from <https://search.proquest.com/docview/909870791/abstract/30C87A63AF4D4BB1PQ/1>
- Keeley, M. P. (2016). Family communication at the end of life. *Journal of Family Communication*, 16(3), 189–197. <https://doi.org/10.1080/15267431.2016.1181070>
- Kellehear A, Pugh E, & Atter L. (2009). Home away from home? A case study of bedside objects in a hospice. *International Journal of Palliative Nursing*, 15(3), 148–152.

- Kirk S (2002) Patient preferences for a single or shared room in a hospice, *Nursing Times*, 98, 50, 39-41
- Leighl, N. B., Butow, P. N., & Tattersall, M. H. N. (2004). Treatment decision aids in advanced cancer: when the goal is not cure and the answer is not clear. *Journal of Clinical Oncology*, 22(9), 1759–1762. <https://doi.org/10.1200/JCO.2004.02.166>
- Loprinzi, C. L., Schapira, L., Moynihan, T., Kalemkerian, G. P., von Gunten, C., & Steensma, D. (2010). Compassionate honesty. *Journal of Palliative Medicine*, 13(10), 1187–1191. <https://doi.org/10.1089/jpm.2010.9777>
- Loprinzi, C. L., Johnson, M. E., & Steer, G. (2000). Doc, how much time do I have? *Journal of Clinical Oncology*, 18(3), 699–701.
- Mack, J. W., & Smith, T. J. (2012). Reasons why physicians do not have discussions about poor prognosis, why it matters, and what can be improved. *Journal of Clinical Oncology*, 30(22), 2715–2717. <https://doi.org/10.1200/JCO.2012.42.4564>
- Mack, J. W., Wolfe, J., Grier, H. E., Cleary, P. D., & Weeks, J. C. (2016). Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. *Journal of Clinical Oncology*. <https://doi.org/10.1200/JCO.2006.06.5326>
- Maidment, J. (2006). The quiet remedy: a dialogue on reshaping professional relationships. *Families in Society: The Journal of Contemporary Social Services*, 87(1), 115–121. <https://doi.org/10.1606/1044-3894.3491>
- McGhee, G., Marland, G. R., & Atkinson, J. (2007). Grounded theory research: Literature reviewing and reflexivity. *Journal of Advanced Nursing*, 60(3), 334–342. <https://doi.org/10.1111/j.1365-2648.2007.04436.x>
- McKee, M., Kelley, M., Guirguis-Younger, M., Maclean, M., & Nadin, S. (2010). It takes a whole community: the contribution of rural hospice volunteers to whole-person palliative care. *Journal of Palliative Care*, 26, 103–111. <https://doi.org/10.1177/082585971002600206>
- Mission. (n.d.). Retrieved September 19, 2019, from Clarehouse website: <https://www.clarehouse.org/about-us/mission/>
- Morris, S., Wilmot, A., Hill, M., Ockenden, N., & Payne, S. (2013). A narrative literature review of the contribution of volunteers in end-of-life care services. *Palliative Medicine*, 27(5), 428–436. <https://doi.org/10.1177/0269216312453608>
- Morris SM, Payne S, Ockenden N, et al. (2015) Hospice volunteers: bridging the gap to the community? *Health Soc Care Community*, 25, 1704–1713

- Murata, H. (2003). Spiritual pain and its care in patients with terminal cancer: Construction of a conceptual framework by philosophical approach. *Palliative and Supportive Care*, 1(1), 15–21. <https://doi.org/10.1017/S1478951503030086>
- Narayan, A., & Simonet, V. D. (2014). *Clarehouse Program Evaluation*. Source unpublished.
- Neff, P., Lyckholm, L., & Smith, T. (2002). Truth or consequences: What to do when the patient doesn't want to know. *Journal of Clinical Oncology*, 20(13), 3035–3037.
- Neergaard, M. A., Olesen, F., Jensen, A. B., & Sondergaard, J. (2008). Palliative care for cancer patients in a primary health care setting: Bereaved relatives' experience, a qualitative group interview study. *BMC Palliative Care*, 7(1), 1-8. <https://doi.org/10.1186/1472-684X-7-1>
- Neergaard, M. A., Olesen, F., Jensen, A. B., & Sondergaard, J. (2010). Shared care in basic level palliative home care: Organizational and interpersonal challenges. *Journal of Palliative Medicine*, 13(9), 1071–1077. <https://doi.org/10.1089/jpm.2010.0036>
- NHPCO Facts and Figures: Hospice care in America. Alexandria, VA: National Hospice and Palliative Care Organization; 2018. Retrieved from https://39k5cm1a9u1968hg74aj3x51-wpengine.netdna-ssl.com/wp-content/uploads/2019/07/2018_NHPCO_Facts_Figures.pdf
- Patrick, D. L., Engelberg, R. A., & Curtis, J. R. (2001). Evaluating the quality of dying and death. *Journal of Pain and Symptom Management*, 22(3), 717–726. [https://doi.org/10.1016/S0885-3924\(01\)00333-5](https://doi.org/10.1016/S0885-3924(01)00333-5)
- Peabody, F. W. (2015). The care of the patient. *JAMA*, 313(18), 1868–1868. <https://doi.org/10.1001/jama.2014.11744>
- Polimeni, A.-M., & Moore, S. (2002). Insights into women's experiences of hospital stays: Perceived control, powerlessness and satisfaction. *Behaviour Change*, 19(1), 52–64. <https://doi.org/10.1375/bech.19.1.52>
- Potter C. (2008). The delivery of dignity when caring for older people. *British Journal of Community Nursing*, 13(9), 430–432.
- Rowlands, J., & Noble, S. (2008). How does the environment impact on the quality of life of advanced cancer patients? A qualitative study with implications for ward design. *Palliative Medicine*, 22(6), 768–774. <https://doi.org/10.1177/0269216308093839>

- Stern, P. N. (2011). *Essentials of accessible grounded theory*. Walnut Creek, Calif: Left Coast Press.
- Stuart, April, MPH. (2015, May 5). *Clarehouse Outcome Pathways-End-of-Life Care Program Adherence Summary*. Department of Medical Informatics, University of Oklahoma-Tulsa.
- Sweet, V. (2013). *God's hotel: A doctor, a hospital, and a pilgrimage to the heart of medicine* (Reprint edition). Riverhead Books.
- Teno, J. M., Shu, J. E., Casarett, D., Spence, C., Rhodes, R., & Connor, S. (2007). Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. *Journal of Pain and Symptom Management*, 34(2), 120–125. <https://doi.org/10.1016/j.jpainsymman.2007.04.014>
- Teno, J. M., Casarett, D., Spence, C., & Connor, S. (2012). It is “too late” or is it? Bereaved family member perceptions of hospice referral when their family member was on hospice for seven days or less. *Journal of Pain and Symptom Management*, 43(4), 732–738. <https://doi.org/10.1016/j.jpainsymman.2011.05.012>
- Ulrich, R., & Quan, X. (2004). *The Role of the Physical Environment in the Hospital of the 21st Century: A Once-in-a-Lifetime Opportunity*. 69.
- Vanderstichelen, S., Houttekier, D., Cohen, J., Van Wesemael, Y., Deliens, L., & Chambaere, K. (2018). Palliative care volunteerism across the healthcare system: A survey study. *Palliative Medicine*, 32(7), 1233–1245. <https://doi.org/10.1177/0269216318772263>
- Veatch, R. M., & Veatch, L. L. (1994). Hospital Roommates: An interview with a terminally ill patient special section: Healthcare relationships: ties that bind. *Cambridge Quarterly of Healthcare Ethics*, (1), 71–80.
- Williams, A. M., Dawson, S., & Kristjanson, L. J. (2008). Exploring the relationship between personal control and the hospital environment. *Journal of Clinical Nursing*, 17(12), 1601–1609. <https://doi.org/10.1111/j.1365-2702.2007.02188.x>
- Williams, A. M. (2004). Healing Places. *The Canadian Geographer*, 48, 506–508.
- Williams AM & Irurita VF (2004) Therapeutic and non-therapeutic interpersonal interactions: the patient's perspective. *Journal of Clinical Nursing* 13, 806-815.
- Wilson, D. M., Justice, C., Thomas, R., Sheps, S., & al, et. (2005). End-of-life care volunteers: A systematic review of the literature. *Health Services Management Research; London*, 18(4), 244–257.