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DEATH AND DYING IN ASSISTED LIVING

by

AMANDA M. WHITE

Under the Direction of Dr. Mary Ball

ABSTRACT

This study examined death and dying in assisted living (AL) and the various factors that influence these processes. The study is set in a 60-bed assisted living facility outside of Atlanta, Georgia. Data collection methods included participant observation and in-depth interviews with 28 residents and 6 staff. Data were analyzed using the grounded theory approach and focused on the 18 residents who were dying and/or died during the study period. Findings show that AL residents experience a variety of dying trajectories that vary in duration and shape; for the majority of residents, hospice is an important element in their death and dying experiences. In general, death is not communicated or acknowledged formally within the facility. Responses to deaths depend largely on the nature of the relationship the deceased resident had with others.

Findings have implications for how to handle death and dying in AL and to improve residents' experiences.

INDEX WORDS: Death, Death and dying, Assisted living, Nursing home, Dying trajectories, Responses to death, Death attitudes, End-of-life care

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by

AMANDA M. WHITE

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Masters of Arts

in the College of Arts and Sciences

Georgia State University

2009

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2009

DEATH AND DYING IN ASSISTED LIVING

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December 2009

DEDICATION

This thesis is dedicated in loving memory to my beloved Gramma, Catherine Roughen Edwards.

“Gray hair is a crown of splendor; it is attained by a righteous life.” Proverbs 16:31.

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I would like to thank Dr. Mary M. Ball for her continuous guidance, support, and patience. Mary spent so much of her time with countless e-mails, meetings, and phone calls to make my thesis a success and she taught me so much! Her expertise and knowledge of assisted living was so helpful and I admire her passion for improving the lives of older adults. Mary, I couldn't have done this without you.

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CHAPTER 1

INTRODUCTION

Statement of the Problem

The population of older adults is projected to grow at an increasingly fast rate within the near future. By 2030, one in every five Americans will be an older adult (Centers for Disease Control and Prevention, 2005). As the population of older adults grows, assisted living facilities (ALFs) are increasingly being utilized as a long-term care (LTC) option. In addition, more and more ALFs are admitting and retaining older adults with greater physical and cognitive impairment (Golant, 2008). Because many older adults prefer to age in place in an ALF, it is becoming more likely that this setting may be where they die (Newcomer, Flores, & Hernandez, 2008). The numbers of deaths in ALFs range from 14 percent to 22 percent annually (Golant, 2004; Zimmerman et al., 2005). Despite the likelihood of death in Assisted Living (AL), research addressing death and dying and end-of-life care in AL is limited (Sloane et al., 2003). It is extremely important to understand the process of death in AL because this setting has become and will continue to be a very popular LTC option for older adults as the older adult population continues to grow in the coming decades.

Research Aims

The main goal in this research is to understand death and dying in AL and the various factors that influence these processes. The research will address the following specific research aims:

- 1) To understand the processes of death and dying in AL.
- 2) To understand how individual-, facility-, and community-level factors influence death and dying in AL.

Literature Review

The population of older adults in the United States is projected to grow significantly in the near future. From 2000-2010, the 75-84 age group will increase by four percent, and the 85+ age group will increase by 44 percent (U.S. Census Bureau, 2004). After the first decade of this century, the number of older adults will continue to increase drastically at an even faster pace. From 2010-2030, the 75-84 age group will increase more than 86 percent, and the 85+ age group will increase by 57 percent (U.S. Census Bureau, 2004). By 2030, one of every five Americans will be an older adult (Centers for Disease Control and Prevention, 2005).

The growth in the number of older adults results in the increase in the specific needs of this population. With our current older adult population, the proportion of those with some disability is increasing with age: nine percent among adults 75-79 and 35 percent among adults 85 and older (Golant, 2008). Therefore, unless there are major medical and therapeutic discoveries, it is realistic to predict even larger numbers of frail older adults in the future (Cohen, Weinrobe, Miller & Ingoldsby, 2005), resulting in an increase in the need for LTC that offers supportive services.

Assisted Living

Until recently, older adults with chronic illnesses would get care in their own home or at a skilled nursing facility (Hyde, Perez, & Reed, 2008). However, in the past 15 years, a rapidly growing LTC option that is currently utilized by more than one million older adults who want and need assistance is assisted living (Golant, 2008). Though there are variations across states, ALFs are mainly non-medical, community-based living environments that provide residents with shelter, board, 24-hour staff and personal care services such as bathing, dressing, and grooming (Hawes, Rose, & Phillips, 1999; Golant, 2008). The majority of ALFs are private pay and cater

to the middle and upper classes (Golant, 2008). Though most older adults prefer to age in place within their own homes, ALFs are an increasingly popular setting in which to grow older, and they are considered more “home-like” and less restrictive than nursing homes (Ball et al., 2004). States across the country support AL because of the expectation that older adults will be able to age in place and either avoid or delay nursing home placement (Newcomer, Flores, & Hernandez, 2008).

Characteristics of Facilities

ALFs vary in design and size. Some are stand-alone buildings where a narrow range of care is provided (Golant, 2008). Other ALFs may be divided by floors or sections or even different buildings in order to provide varying levels of care (Golant, 2008). Some facilities have a few beds, while others have hundreds of beds (Zimmerman, Sloane, & Eckert, 2001). ALFs also vary widely in ownership and policies, with very different patterns in the services and accommodations offered and the amount of staffing provided (Hawes, Phillips, Rose, Holan, & Sherman, 2003; Mollica & Johnson-Lamarche, 2005). Some ALFs have staff that provides nursing services as complex as intravenous medication and wound care, while others offer only light care from staff, catering to residents who are minimally dependent or frail (Golant, 2008). Though most ALFs are private pay (Hawes et al., 1999), in a small number of ALFs, costs are subsidized by government programs such as Supplemental Security Income and Medicaid (Golant, 2008). One definition of AL is unlikely to be formed due to the variety of settings and regulations under which it operates (Zimmerman & Sloane, 2007). In fact, each state has developed its own definition of AL based on different factors such as the type and intensity of care that is provided, size, structure, financing, and the level of care provided (Zimmerman & Sloane, 2007). In some states, AL is a detailed model with a service philosophy focused on

consumers, private apartments or units, and a wide range of services (Mollica & Johnson-Lamarche, 2005). In other states, the licensing categories of residential care have been combined under a new general set of AL rules that might cover the new model of AL, as well multi-unit elderly housing, board and care, congregate housing, and sometimes even adult family or foster care (Mollica & Johnson-Lamarche, 2005). In Georgia, ALFs are designated “personal care homes” and include a wide range of facilities under this definition with no limitations on size or resident age (except residents have to be over age 18).

Characteristics of Assisted Living Residents

AL residents typically are less impaired than residents of nursing homes in terms of their activities of daily living (ADL) needs and degree of cognitive impairment (Golant, 2008; Reinardy & Kane, 2003), but studies have found that the boundaries between ALFs and nursing homes are becoming increasingly blurred as more and more ALFs admit and retain residents with higher physical and cognitive impairments (Golant, 2008). Though ALFs are regulated by states, they still have a great deal of control over which residents they admit and retain, while also determining what services will be provided (Stone & Reinhard, 2007). Golant (2008) discusses how some facilities cater to residents who are more independent and minimally frail while others accept residents that are almost as impaired physically and cognitively as those who reside in nursing homes.

The average age of an older adult who enters an ALF is 83 years (American Association of Homes and Services for the Aging, 2006). The typical AL resident is an 80 year old White female who is widowed and independently ambulates, but requires assistance with two ADLs (Mezey, Dubler, Mitty, & Brody, 2002). A study conducted in four states found that degree of resident impairment varied across three types of ALFs: 1) small facilities with fewer than 16

beds; 2) newer and purpose-built larger facilities; and 3) more traditional larger facilities. The greatest ADL dependencies were in bathing (52.3%-62.5%), personal hygiene (21.8%-45.3%), and dressing (22.8%-42.9%); over half of residents used mobility devices (51.9%-62.9%) (Morgan, Gruber-Baldini, & Magaziner, 2001). The facilities with fewer than 16 beds had the highest percentages of ADL dependency, followed by the newer, purpose-built larger facilities, and then the traditional facilities with the lowest range of ADL dependencies (Morgan, et al., 2001). This study also found that the sample of smaller ALFs with fewer than sixteen beds showed the highest percentages of dependencies on all ADL items, while residents in the larger, traditional facilities were significantly less impaired (Morgan, et al., 2001).

AL residents also have many different health concerns and several co-morbid conditions (Hawes et al., 2003, Morgan, et al., 2001). A recent industry-wide survey found that almost every resident in AL has one or more chronic conditions and takes an average of eight medications daily (ALFA, 2006). In the four-state ALF study referred to above, the most common health problems were a combination of arthritis, rheumatism, and degenerative joint diseases, followed by high blood pressure and vision problems, which included glaucoma, cataracts, and macular degeneration; one in every five or six residents required hospital admission within a six-month period (Morgan et al., 2001).

Cognitive impairment also is common in ALFs. A national study conducted in 1999 (Hawes et al., 2003) reported that 34 percent of AL residents had moderate to severe cognitive impairment. The previously mentioned four-state ALF study found more severe cognitive impairment in the smaller facilities with fewer than sixteen beds (31.4%) compared to the larger, traditional facilities with only 15.4% severe impairment (Morgan et al., 2001). More and more

facilities are trying to meet the needs of residents with cognitive impairments, and 61 percent of ALFs currently provide dementia care (Metlife Mature Market Institute, 2006).

Length of Stay in Assisted Living

According to the National Center for Assisted Living (2008), the average length of time a resident lives in an ALF is 27 months. Because many residents prefer to age in place in AL, this setting may be where they die, but increasing frailty and declining health also can result in an ALF discharging a resident as well (Frank, 2001). Although most ALFs typically are not allowed by law to provide skilled nursing care (24 hour-a-day skilled nursing oversight or daily skilled nursing services) (Mollica & Johnson-Lamarche, 2005), in many states facilities may apply for a waiver to retain residents whose needs exceed the level of care that is permitted (Ball et al., 2004, Mollica & Johnson-Lamarche, 2005).

Ball et al. (2004) found that whether or not residents were able to remain in an ALF was based mainly on the “fit” between the capacity of residents and facilities to manage resident decline. Resident capacity to manage decline is related to his or her own knowledge, attitudes, and behaviors associated with health promotion and treatment compliance (Ball et al., 2004). Facility capacity is influenced by factors such as design characteristics, including handrails, walk-in showers, wider doorways, and grab bars, staffing levels, and a facility’s philosophy regarding aging in place (Ball et al., 2004, 2005; Mollica & Jenkins, 2001). ALFs have responded to the desire of older adults wanting to age in place in one of two ways: using a “constant approach” where accommodations aren’t made for residents who need more assistance or the “accommodating approach” in which facilities add services or relax requirements in order for residents to stay longer (Frank, 2001). Golant (2004) found that ALFs were more tolerant of higher levels of frailty in their retention and discharge policies than they were in their admission

policies. More than a quarter of AL residents without dementia will spend the rest of their lives in this setting, while nearly half of residents in AL dementia care units will remain there until the end of their lives (Hyde et al., 2008). Studies indicate that the number of deaths in ALFs ranges from 14 to 22 percent annually (Golant, 2004; Zimmerman et al., 2005).

Death and Dying in Long-term Care

Despite the likelihood of death in ALFs, research addressing death and dying and end-of-life care in this setting is limited (Sloane et al., 2003). Most research that has focused on the dying experience has been in acute care hospital settings and involves inadequate pain management and the absence of emotional and spiritual support (Kayser-Jones, 2002). One explanation offered for the lack of research concerning death in LTC is the need for practical and reliable instruments to measure and describe the experience (Tilden, Tolle, Drach, & Hickman, 2002).

Ethnographic studies conducted in nursing homes (Gubrium, 1975; Kayser-Jones, 2002; Marshall, 1975; Savishinsky, 1991; Shield, 1988) provide the most comprehensive information on the dying process in LTC. These studies examine the main factors that influence the dying experience, the socialization of dying, the attitudes staff and residents have towards death, how and by whom the news of death is spread throughout the facility, and what events happen after a death has occurred (Gubrium, 1975; Kayser-Jones, 2002; Marshall, 1975; Savishinsky, 1991; Shield, 1988).

Living and Dying at Murray Manor, (Gubrium,1975) is based on a qualitative research study carried out in 1973 in which the author spent several months conducting fieldwork in a nursing home, sometimes working alongside staff members. *The Ends of Time: Life and Work in a Nursing Home* (Savishinsky, 1991) also is based on ethnographic research, in which

Savishinsky and his students spent seven years in a nursing home in upstate New York observing, participating, and interviewing the residents, family, and staff. *Uneasy Endings* (Shield, 1998), another ethnography, is derived from Shield's 14-month qualitative study of a large nursing home with 200 residents, where she observed and participated in nursing home life. Marshall (1975) compares the dying experiences of residents in a continuing care retirement community (CCRC) and a Catholic run nursing home.

A limited number of more recent studies examine end-of-life experiences in both ALFs and nursing homes (Bern-Klug, 2009; Cartwright, 2009; Munn et al., 2008; Sloane et al., 2003). Bern-Klug (2009) developed a framework for categorizing social interactions related to end-of-life care in nursing homes. Cartwright (2009) examined what factors promote good hospice care in AL. Munn et al. (2008) studied five nursing homes and eight ALFs in North Carolina, using focus groups with residents, family, and staff. Sloane et al. (2003) analyzed data from 224 staff and family members from 55 ALFs and 26 nursing homes across four states. In what follows below, I review the findings from the aforementioned studies and other relevant work.

Dying Trajectories

Glaser and Strauss (1968) in their classic treatise on death and dying in hospitals emphasize the importance of identifying the dying status in order that it may be reacted to as dying. Bern -Klug (2009), however, in considering social interactions at the end of life, points out the ongoing challenge of determining when an individual is in fact at the end of life. At the root of the challenge is the very nature of dying. As Marshall (1975: 355) notes, dying takes place in a social context and as such is a "social event." The dying state thus is defined by the individual dying as well as by others, and this perception influences how the individual dying and others behave. Glaser and Strauss (1968: 6) refer to the socially defined course of dying as a

dying trajectory. A dying course, they suggest, has both duration, the length of the dying course, and shape, the slope of the residents' decline as they approach death.

Marshall found that although residents in both the CCRCs and nursing home considered these settings as "places to die," they differ in the way in which dying trajectories are organized. He reported that in the nursing home, only in the very last stages of life is a resident considered to be dying. Residents thus are defined as alive when they move to the home and move to the dying status only when they become seriously ill or require intensive care. In the CCRC, Marshall (1975: 359) states, death is more a part of everyday life and residents "organize themselves as a community of dying."

Bern-Klug (2009) found that when a resident is designated as dying, the social interactions among family, staff, and physicians greatly impact the end-of-life care the resident will receive. Bern-Klug (2009) developed a framework of five categories to classify the social interactions related to the dying status: *dying allowed*, *dying contested*, *mixed message dying*, *not dying*, and *not enough information*. These categories indicate that even informed people can disagree about the point at which dying begins and this disagreement can lead to a lack of consensus involving the care plan goals for a resident (Bern-Klug, 2009).

Staff and Residents Attitudes Toward Death

Ethnographic studies conducted in nursing homes indicate that residents are more comfortable discussing and confronting death than are staff members (Gubrium, 1975; Savishinsky, 1991; Shield, 1988). In fact, Shield (1988) found that whereas residents "talked and joked freely about death", staff seemed "repulsed" by and avoided such discussions (p. 69). One reason offered for the tendency of staff to avoid death talk was that these conversations served as a reminder of their own death. Savishinsky (1991) described the comments of one nursing home

staff member reflecting this viewpoint: “Death is a taboo subject,” and “...we (society) avoid old people because they remind us of death” (p. 161). Another reason found by Shield (1988) was the desire on the part of staff to protect and shield residents from death because it is unpleasant. However, other research suggests that the tendency for staff to avoid issues of death can lead to misguided attempts to get the residents to think about positive things, no matter how superficial it may be for the residents (Smith, 2000).

Although both residents and staff are constant witnesses to death in the nursing home setting, these ethnographic studies indicate that residents tend to be pragmatic about death and consider it a natural part of growing older (Gubrium, 1975; Savishinsky, 1991; Shield, 1988). Gubrium (1975) found that residents at the nursing home knew and accepted that they were dying; the actual time of the death was the only unknown for them. Marshall (1975) observed that residents’ principal attitude toward impending death at the Catholic run nursing home was that of resignation, usually religiously phrased in comments such as, “Nobody’s the boss but the Lord” (p.359) or “You are just living until the Good Lord’s ready to take you” (p.360). For these nursing home residents, death provided a release from present discomforts (Marshall, 1975). In contrast, Marshall (1975) observed that the majority of residents at the CCRC felt that death was likely to come just on time or too late, and they felt they had reached a stage of their lives in which their impending death was legitimate and appropriate. However, a study conducted in a CCRC with 272 residents, found that many AL and nursing home residents referred to death as an escape, which the authors suggest represented apathy, boredom, and a desire to avoid a further decline in health status (Shippee, 2009).

Assisted living research has shown that religiosity can influence how residents experience dying and death. One study conducted in 17 ALFs in Georgia found that religious

beliefs can help residents prepare for their own deaths and also help them to maintain continuity in their lives in the face of change, such as the death of fellow residents (Patterson et al., 2003). A strong religious faith also serves to relieve anxiety about dying because of belief in an afterlife (Patterson et al., 2003). Marshall (1975:360) found that for residents in the Catholic nursing home, their Catholic faith guided their belief that individuals have no control over the time of death, which rather is predestined and according to “God’s will.” Other AL research has shown that commonality in religious beliefs can bring residents closer together (Eckert, Zimmerman, & Morgan, 2001), possibly decreasing the negative impact of a fellow resident’s death.

The Role of Family

Most residents living in AL depend on their families for various types of support (Ball et al., 2005). A study that reviewed current literature on family involvement in AL found that families provide a large range of assistance with instrumental activities of daily living, but provide minimal personal care (Gaugler & Kane, 2007). In fact, families may provide the majority of instrumental care since AL has an emphasis on control, privacy, and autonomy for its residents and reluctance to provide intensive 24-hour supervision (Gaugler & Kane, 2007). Patterns of family support, or kin-work, vary in composition and the degree, with some family members typically shouldering more of the care burden than others (Ball et al., 2005). Family support also influences a resident’s ability to age in place (Ball et al., 2004, 2005).

Although no studies have specifically addressed the family role in how residents experience death and dying in AL, it is likely that their roles will influence these processes, whether through family members increased care roles or through their involvement in other aspects, including health care decision-making, such as whether or not to use hospice services in the facility, and the performance of various rituals surrounding the death event.

Residents can also receive support from spouses while living in AL (Kemp, 2008). In fact, married residents rely more on their spouses for emotional and instrumental support than on other family members (Kemp, 2008). Married couples in AL therefore are likely to experience death and dying more acutely than other residents because of their significant loss of companionship and support with the death of a spouse.

The Death Event

Spreading the News

Ethnographic research in nursing homes also indicates that staff not only avoid the subject of death (Gubrium, 1975; Savishinsky, 1991; Shield, 1988), but they also actively try to muffle and distance themselves from death events (Savishinsky, 1991; Shield, 1988). Shield (1988) found that with an impending death, most staff seemed to withdraw and discussed the incident quietly so that residents would not hear them. Gubrium (1975) reported that in order to contain death news, staff would close doors, pull curtains, feign patient treatment, and remove the body of the deceased while residents were at meals. However, Gubrium (1975) witnessed staff talking more audibly and openly about death around residents who were not considered to be alert. As one staff member explained “It’s not good to talk about death in front of the more alert ones. If they got frightened, it would just make your work that much harder” (Gubrium, 1975, p. 207). Shield (1988) found that staff also tried to shield the residents when a fellow resident died because they wanted to protect them from the sadness and unpleasantness of the reality of death. Another study found that even though nursing home and ALF managers believed residents were accepting of their own deaths, 80 percent of facilities still concealed deaths from other residents (Katz, Sidell, & Komaromy, 2001). However, Marshall (1975) found at both the nursing home and CCRC in his study that residents were made aware of their fellow

resident's deaths. At the nursing home, a public funeral was a frequent occurrence, and at the CCRC, short obituary notices were posted around the campus (Marshall, 1975).

In contrast to staff, nursing home research indicates that residents are "often eager to be informed" when a death of a fellow resident has occurred (Gubrium, 1975, p. 69). Similarly, Shield (1988) reported that even though there is little or no disclosure from the staff, "...the news of the death travels quickly and stealthily among the residents" (p.70). Gubrium (1975) observed that some residents serve as informants and take advantage of the physical space to obtain death news by keeping watch of specific places such as the ambulance ramp in the back of the nursing home. Once a death is confirmed, Gubrium (1975) found that news is spread easily among the residents at meals in the dining room or in other places where gatherings occur. Gubrium (1975) also found that many services that were utilized daily by residents, such as the beauty shop, were located in places that made observing death of other residents unavoidable. Also, because residents live in such close proximity to each other, they are often accidental witnesses to death and therefore view death as a natural occurrence within the facility (Munn et al., 2008). Consequently, they sometimes become the source of information without having tried. Gubrium's 1975 study suggests that residents sometimes on occasion are grateful for the news of a death because sharing this news gives them something to do and helps to pass the time.

Death Rituals

Nursing home research indicates that staff are responsible for preparing the dead body for removal by washing it and removing personal belongings such as glasses, jewelry, and dentures (Gubrium, 1975). Each facility has its own method of removing the body. In some facilities, staff make sure the residents do not witness the removal of a body by closing doors and removing all residents from hallways and general sitting areas (Munn et al., 2008). In other facilities, staff

consider hiding the removal of a body unnecessary and simply remove bodies through the main lobby or entrance (Gubrium, 1975; Munn et al, 2008), though some residents think this practice of public removal is undignified (Munn et al., 2008).

There is some evidence that facilities acknowledge death of residents with customary funeral rituals (Moss, Moss, Rubinstein, & Black, 2003). Yet, in a national study of nursing homes, less than half of facilities in the sample reported that they had any type of memorial service for deceased residents in the previous year (Moss, Braunschweig, & Rubinstein, 2002). In fact, a study of 121 nursing homes in Michigan found that administrators in only half of study facilities sent a sympathy card to the deceased's family, whereas in 98 percent they gave no visit, phone call, or written material to the bereaved family (Murphy, Hanrahan, & Luchins, 1997). Shield (1988) observed no notices or memorial services when residents died in the nursing home she studied. On one occasion, Shield (1988:170) observed a resident organizing a memorial service in protest for a friend and fellow resident who had recently died, saying, "When someone dies, it is as if the person never even existed. They [staff] pretend nothing has happened." In contrast, in Marshall's (1975) research of a Catholic-run nursing home, death received considerable ritual treatment with a public funeral led by a priest for each resident who died. Another study reported that staff from nursing homes discussed the importance of having services in the facility where both staff and residents could acknowledge the death of a resident (Brazil et al., 2004). Based on his research, Savishinsky (1991) suggests that having established procedures for dealing with death that address the social and emotional impact on those left behind is important. This study also recommended that facilities implement policies that give staff, residents, and visitors a way to express and experience grief, while at the same time protecting those who do not wish to participate (Savishinsky, 1991). Shield's (1988) work

indicates that the development of transition-easing rituals can promote the growth of group solidarity and a greater sense of community within the facility. Assisted living research indicates that individuals at the corporate level or the facility administrators set policies regarding how deaths of residents will be handled (Ball et al., 2005).

Personal Responses to Death

Research shows varying responses to death by both staff and residents (Gubrium, 1975; Munn et al., 2008; Savishinsky, 1991; Shield, 1988). Gubrium (1975) reported that following a resident's death at the nursing home, there was no general sadness among residents because of a common belief that death is an expected occurrence and that those who die are done with the "worry" associated with being a "burden" on others (Gubrium, 1975, p. 203). Other studies found that residents seemed to be matter of fact about their own death and the deaths of their peers, offering comments such as, "Well, we're all here to die" (Shield, 1988, p. 191) or "I'm ready when my time comes" (Savishinsky, 1991, p. 183) or "If I died I'm going to die and there's nothing to it. I know I'm getting older and the day's shorter. But I don't worry about it" (Marshall, 1975, p.359-360).

Gubrium (1975) found that nursing home staff were even less upset than residents when a death occurred, because they regularly cared for dying residents, and thus observed the dying process over a period of time, and typically prepared the bodies after death. In contrast, other research (Ball, Lepore, Perkins, Hollingsworth, & Sweatman, 2009; Moss et al., 2003; Savishinsky, 1991) indicates that staff members react in varying ways to death, depending on the emotional closeness they share with the resident. In fact, staff often have closer relationships with residents who do not have family support, and some even assume traditional family roles (Ball et al., 2009). Facility size also can affect relationships between staff and residents. Often

caregivers have a deeper personal relationship with the residents in smaller homes (Ball et al., 2005; Eckert, Zimmerman, & Morgan, 2001). Therefore, staff who work in a smaller facilities may experience more grief when a resident dies. Resident tenure is also a contributing factor; Savishinsky's (1991) nursing home study found significant grief among staff, who felt as though they had lost a family member when a resident who had lived in the home for seventeen years passed away.

The Role of Hospice

Hospice is an interdisciplinary approach to the care of terminally ill patients and their families that incorporates social and spiritual care, management of physical symptoms, and psychological and bereavement support (Moon & Boccuti, 2002). According to the Medicare website (2009), in order to receive the Medicare hospice benefit, a physician must certify that a person has less than six months to live. The length of time a person stays in hospice influences the degree to which the program's full benefit is achieved; short lengths of stay do not allow for physical symptoms to be controlled effectively or emotional issues to always be handled sufficiently (Welch, Miller, Martin, & Nanda, 2008).

Some evidence exists that hospice services have a positive impact on end-of-life care in nursing homes and ALFs (Munn et al., 2008). Long-term care staff tend to view hospice workers as experts in pain management (Munn et al., 2008). In fact, one study of 26 nursing homes and 55 ALFs reported that residents who received hospice services received more pain treatment and more assistance with eating, drinking, and mouth care than residents without these services (Munn, Hanson, Zimmerman, Sloane, & Mitchell, 2006). Cartwright (2009) found that high AL staff commitment to the resident dying in the ALF and respectful collaboration among multiple care providers were associated with promoting good care for AL residents on hospice.

Administrator support for hospice and for allowing residents to die in the ALF setting was also a significant factor for promoting good end-of-life care (Cartwright, 2009).

Research in nursing homes indicates that whether or not a resident receives hospice services and for how long depends on staff members' abilities to recognize terminal decline (Welch et al., 2008). This study points out the importance of increased training in recognizing terminal decline and understanding the range of hospice services for nursing home staff (Welch et al., 2008). One AL study found hospice use to be higher than previously reported and discussed how hospice use has most likely increased in LTC because of improved awareness and sensitivity to end-of-life care issues, with staff being more knowledgeable about hospice enrollment criteria (Munn et al., 2006). Research has shown that AL and nursing home staff view hospice as a valuable source of training and bereavement services (Munn et al., 2008). Other research suggests that death education should discuss the universal stages and responses of grief, because of the fact that knowing and understanding grief can help staff to affirm and normalize the process of grieving for themselves and their residents (McCall, 1999). When staff are educated about death and dying, they are better able to provide support for one another and their residents, rendering their work less stressful and more manageable (Katz et al., 2001).

In summary, the existing literature regarding death and dying in LTC settings shows that these processes are ongoing and expected occurrences and become a part of the routine experiences of residents and staff. Research also makes clear that the health conditions typical of LTC residents, together with the often subjective nature of the dying status, make it difficult to designate a point of dying and to characterize residents' dying trajectories. Evidence exists, though, that despite the regularity of death, the event often is not communicated or acknowledged in these settings in any formal way.

Studies further point out that the participants in LTC settings, including residents, can experience death and dying in different ways and that multiple, multilevel factors, including the subjectivity surrounding dying, can affect these experiences. Other factors indicated in the literature include the use of hospice, the attitudes and beliefs, particularly religion, of participants, residents' family relationships (especially between spouses), and various policies and practices of the LTC organization.

The literature regarding hospice indicates that hospice services are being used increasingly in LTC settings, including AL. Studies show that hospice use benefits residents and their families as well as staff and that outcomes depend on participants' attitudes, the support of the administrative staff, and on how services are integrated into ongoing facility care practices.

Yet, much still remains to be learned about death and dying in the AL setting. Research is needed that specifically focuses on how residents, staff, and residents' family members experience these processes, including how and when the dying status is designated and communicated, what happens when a death occurs, who is specifically involved in the death and dying events, and how do participants in the setting respond to death and dying. It is also important to know how participants' experiences vary depending on factors relating to residents, facilities, and communities. Since an increasing number of residents in AL are being diagnosed with dementia, studies that address how dementia affects how death and dying is handled in AL is greatly needed. Research that focuses on how residents' families influence the death and dying process is important since many residents in AL depend on their families for different kinds of assistance. More research regarding death and dying in AL will help professionals provide better care to dying residents, encourage more effective policies and practices regarding death and

dying, and possibly encourage needed emotional and supportive services to the people left behind after residents' deaths.

Research Aims and Questions

The main goal in this research is to understand death and dying in AL and the factors that influence these processes. Little research examines death and dying in ALFs. It is extremely important to understand these phenomena in AL because this setting will continue to be a popular LTC option for the growing older adult population. Through my research, I will add to the death and dying literature in ALFs and provide important information to older adults, their families, and the facilities that care for them, as well as policy makers. This project will address the following aims and questions:

- 1) To understand death and dying in AL.
 - A. What are the components of these processes?
 - B. Who participates in the processes?
 - C. How are participants involved in the processes?
 - D. How do participants respond to the processes?
- 2) To understand how individual-, facility-, and community-factors influence death and dying in AL.

- A. How do individual factors (e.g., residents' family relationships, disability) influence death and dying?

- B. How do facility factors (e.g., facility size, policies) influence death and dying?

- C. How do community factors (e.g., size and location) influence death and dying?

CHAPTER 2

RESEARCH METHODS

The Primary Study

This research study was a secondary analysis of data from a larger, three-year study funded by the National Institutes on Aging entitled “Negotiating Social Relationships in Assisted Living: The Resident Experience.” The Principal Investigator for the study was Mary Ball. My role in this study had been to conduct qualitative and quantitative interviews and participant observation, write field notes, and transcribe recorded qualitative interviews.

Primary Study Aims

The overall goal of the larger study was to learn how to create an environment that maximizes residents’ ability to negotiate and manage their relationships with other residents in the AL setting. The specific research aims were:

- 1) To learn how residents experience their relationships with other residents in the AL setting.
- 2) To understand how individual, sociocultural, and environmental factors shape how residents experience their relationships with other residents in the AL setting.
- 3) To identify successful strategies of AL residents and staff that help residents negotiate and manage social interactions and relationships with other residents.

Research Setting

Research was conducted in ALFs located in and around metro Atlanta, Georgia. ALFs in Georgia are called “personal care homes,” with no restriction on size or age of resident (except that all residents must be over age 18). A wide range in size and types of facilities are included

under Georgia's definition of personal care homes. ALFs in Georgia are licensed and regulated by the Georgia Office of Regulatory Services. Data suggest that AL residents in Georgia resemble the national profile of a population that is predominantly female and becoming increasingly impaired (Ball, et al., 2000; Golant, 2008).

Research Sample

The research sample during the first year of the study consisted of three facilities that varied according to size, location, design, and resident profiles, all factors that are expected to influence the relationships residents have with one another. Participating homes were designated by colors (purple, green, and orange) to protect the identity of the homes and residents.

The Orange Home was a corporately-owned, for-profit facility that catered to 60 middle and upper class African Americans. It was located in Atlanta and had an AL section with two floors and a locked unit for residents with dementia. All residents were African American and approximately one-third were male. The average monthly costs for a unit ranged from \$1,995 to \$3,995, with four different floor plans available. The Orange Home was selected because of the limited research focusing on African Americans in ALFs and because it provided a setting in which to better understand the influence of race on resident relationships.

The Green Home was a corporately-owned, non-profit facility that catered to Jewish older adults. It was located in a large suburb area outside of Atlanta and had an AL section with two floors and an extra care unit for residents with dementia. The Green Home had 40 residents, all were White and 99 percent were Jewish. The average costs for a unit ranged from \$2,300 to \$3,800 per month. Because meals and activities in the Green Home were organized around Jewish culture and the majority of residents were Jewish, it was selected to show the influence of ethnicity and religion on resident relationships.

The Purple Home was a corporately-owned, for-profit facility with 83 residents. It was located in a small town outside of metro Atlanta and consisted of two separate AL buildings, each with 30 residents, and two independent living buildings. Almost all residents were White and the majority were female. The average costs for a unit ranged from \$2,985 to \$3,475, with three different floor plans available. The small-town location of the Purple Home was expected to influence residents' relationships with each other because of the likelihood that some residents may have know each other before moving to the facility.

Data Collection Methods

The study used both qualitative and quantitative methods. The primary methods of data collection used in all study homes were: 1) face to face interviews with administrators, direct care staff, and residents; 2) informal interviews with residents, administrative and care staff, and residents' family members and friends; and 3) participant observation.

In-depth interviews with administrators were conducted during the first month and addressed the facility's policies and procedures regarding residents' relationships, the administrator's knowledge of how residents experience relationships and the factors that influence them, and the administrator's attitude and the facility's philosophy regarding the importance of resident-resident relationships and what behaviors surrounding relationships that were considered appropriate. An additional interview also was conducted with the facility's activity director about her knowledge and attitude regarding relationships and how the activity program influenced how residents experienced their relationships with other residents.

In-depth interviews with direct care staff addressed staff's knowledge of how residents experienced relationships, including their own relationships with residents and the factors that

influenced them, as well as their attitude regarding the importance of resident-resident relationships and what behaviors they considered appropriate.

Type 1 resident interviews, which had a survey format, began the fourth month and collected 1) demographics; 2) health conditions; 3) ADL status; and 4) social networks of selected residents. For Type 1 interviews, we selected residents who were willing and had sufficient cognitive function to participate. Each Type 1 interview lasted 1-3 hours and was conducted in a place within each facility that assured the resident's privacy, mostly in the resident's room.

Type 2 resident interviews were qualitative and addressed residents' life history, circumstances surrounding their moves to AL, day-to-day routines, the quality and quantity of their social interactions and relationships with residents and with other people in and outside the facility, and the influences on and meaning of their relationships with other residents. For the Type 2 interviews, we selected residents who had completed the Type 1 interview, those we believed would be forthcoming in an in-depth interview, and those who represented a variety of individual characteristics and experiences related to relationships with other residents. Each Type 2 interview lasted 1-5 hours and was conducted in the resident's room.

Informal interviewing took place as part of participant observation and began early in the data collection process and continued throughout the duration of the study period. These interviews included spontaneous questions that naturally occurred while interacting with and observing residents as well as more targeting questioning.

Participant observation occurred during regular weekly visits that were scheduled at different days and times throughout the week in order to observe the different facility routines (e.g., meals, recreational activities). Observations included descriptions of the physical

environment and the social environment, including characteristics of people, how they organized themselves into groups, and patterns of interaction. Planned and unplanned and formal and informal activities also were observed. All observations and informal interviews were recorded in detailed field notes. Researchers visited the three homes a total of 522 times and logged approximately 1,580 hours of research time.

Because my research consisted of a secondary analysis of the primary study data and the primary study was approved by Georgia State's Institutional Review Board (IRB), my study did not require separate IRB approval. For purposes of anonymity, I used pseudonyms for the facility, residents, staff, and family members.

The Secondary Study

This study includes only the Purple Home in order to limit the amount of data to be more appropriate for the scope of a thesis. I chose the Purple Home because a substantial amount of deaths occurred in the home during the research year and because it was the location where I collected data. I made weekly visits and witnessed first-hand how death and dying were experienced by the staff, residents, and families in the facility.

Description of the Purple Home

The Purple Home's large campus consisted of five separate buildings connected by covered walkways, which included two three-story independent living buildings that featured one and two bedroom apartments, a building housing administrative offices, a large dining room, a physical therapy room, a beauty salon, game rooms, and a library, and two one-level buildings, the Dogwood and the Azalea, for AL residents. The Dogwood and Azalea each had 30 apartments and its own dining and common areas. The rooms in the AL buildings were situated around the dining room and common areas and three different floor plans were offered. Each

room had a covered patio and a small kitchenette that consisted of a sink and small refrigerator. Although each AL building operated independently with its own staff, activities were scheduled in both buildings daily and AL residents were permitted to go to either building to participate if they chose.

Description of Residents

Eighty-three residents lived in the Purple Home over the course of the study period. Forty-four lived in the Dogwood and 39 lived in the Azalea. Table 1 summarizes the personal characteristics of all the residents. As can be seen, the large majority (91%) are age 80 and over; one fourth are age 90 and over. The large majority are female, and all but three are Caucasian. In addition, the majority use some type of assistive device for mobility. Thirty-two percent use a wheelchair, and 42% a walker. Slightly over one fourth (27%) have dementia.

Table 1: Characteristics of the Secondary Study Participants

Variable	N¹	%
Median Age (\pm sd)	83.18\pm 6.319	
Gender		
Female	65	78%
Male	18	22%
Race		
Caucasian	80	96%
African-American	3	4%
Marital Status		
Never Married	3	5%
Married	10	16%
Divorced	5	8%
Widowed	47	72%
Mobility		
Wheelchair	26	38%
Walker	35	51%
Cane	3	4%
Scooter	2	3%
None	9	13%
Dementia	22	32%

¹ N varies in some categories due to missing information

Data Utilized for the Secondary Study

In order to address my research aims, I used all data that related to death and dying from: 1) in-depth interviews with administrative and direct care staff and residents; 2) informal interviews with residents, staff, and residents' family members and friends; and 3) participant observation. In-depth interviews were conducted with the executive director, the activities director, three care staff, a housekeeper, and 13 residents. All in-depth interviews followed a detailed guide that included specific questions about death and dying.

The interview with the executive director included information regarding how each facility recognized the death of a resident, the facility's experience with hospice, and residents' attitudes about death and dying. Interviews with the activity director and direct care staff addressed how residents reacted when another resident dies, what influenced their reactions, how residents found out about a death that had occurred, what happened after a resident's death, including rituals, and specifics about deaths in the home. Resident interviews asked about any resident friends they had lost while in the home and how they had dealt with the loss and general attitudes toward resident decline and death.

Twenty-eight residents in the Purple Home completed Type 1 interviews, which included social network information. These data provided demographic and social support information.

Researchers visited 210 times and spent 620 hours in the Purple Home during the study period. I examined all data that related to death and dying from field notes, which included data from informal interviews and observations. These data included all those data segments that had been coded by senior researchers with the code: death.

In addition to data that specifically related to death, when appropriate, I utilized additional data that helped me answer Research Aim 2, regarding the factors that influence death

and the dying process. These data included those that specify resident, facility, and community characteristics.

Data Analysis

I used the grounded theory approach (Strauss & Corbin, 1998) to analyze all the types of qualitative data: in-depth interviews with administrators, direct care staff, and residents and field notes from the informal interviews and participant observation. The grounded theory approach consists of a continuous comparative method of inquiry where data collection, hypothesis generation, and analysis occur at the same time. A significant advantage of grounded theory is its flexibility to address new findings and modify initial assumptions made by the researchers. This process involves two analytical procedures: coding and memoing.

The grounded theory approach involves three different types of coding: open, axial, and selective. First, I used open coding to analyze all interview and field note data line by line. As concepts were identified that were based on my research questions, I grouped them into categories and sub-categories (Strauss & Corbin, 1998). Examples of these codes included: activities accompanying death, such as information flow, rituals, and artifacts (e.g., flowers); and or practices associated with dying, such as the use of hospice services and sitters and changes to the physical environment.

I then used axial coding, which connected initial categories to other categories, or subcategories, through what Strauss and Corbin (1998) refer to as a paradigm model. With this type of coding, for example, I examined death-related practices for how they vary across residents, and buildings. Another example was to compare and contrast resident responses to death and dying, with respect to individual factors, such as gender, disability, and facility tenure.

Ideally, I would have achieved the final form of coding (selective coding), but like many scholars, I was unable to identify a core category.

Memoing was also used during the coding process to record my observations, interpretations, insights, and questions about the data. These memos assisted me in making connections across data and in identifying recurring patterns and themes (Strauss & Corbin, 1998). I also created analytical charts to help understand the data and the influence of multi-level factors.

CHAPTER 3

UNDERSTANDING DEATH AND DYING IN AL

Although it could be said that each of the residents at the Purple Home was in fact dying, 18 residents were defined as dying and/or died during the data collection period (June 1, 2008-September 10, 2009). It is on these 18 residents that I focus my analysis.

Table 3.1 shows the personal characteristics and health conditions of these 18 residents. All but one were aged 80 or over, and their combined health conditions include chronic diseases common among AL residents. Half had heart disease or had suffered a stroke. One-third was male, compared to 22% of the total population of the Purple Home.

Table 2: Personal Characteristics and Health Conditions of Residents

Variable	N=18	%
Mean Age	86.7	
Age Range	78-97	
Age		
75-79	1	6%
80-84	7	39%
85-89	6	33%
90-94	2	11%
95-100	2	11%
Gender		
Female	12	67%
Male	6	33%
Race		
Caucasian	18	100%
Marital Status		
Married	6	35%
Divorced	1	6%
Widowed	11	61%
Health Conditions		
Heart Disease	6	33%
Stroke	3	17%
Cancer	2	11%
Diabetes	3	17%
Shingles	2	11%
Parkinson's	2	11% %
COPD	2	11%
Dementia	2	11%

Table 3.2 lists each resident in my sample by name and provides information pertinent to the dying process and/or death. Fourteen of the residents had lived at the Purple Home one year or longer.

Table 3: Individual Information for Sample Residents

Resident Name	Age (in years)	Facility Tenure (in months)	Health Condition(s) / Event	Place of Death	Hospice (yes/no)
Jim Bates	88	1	Brain cancer	Inpatient Hospice Facility	Yes
Natalie Billings	88	42	Unknown	Nursing Home	No
Edith Burchfield	88	15	Heart disease, Shingles	Ambulance in facility parking lot	Yes
George Collins	97	28	Mild dementia	Hospital	No
Elizabeth Cummings	83	12	Stroke, diabetes	Hospital	Yes
Bessie Gunner	78	27	Stroke, Parkinson's, Diabetes	Hospital	No
Walter Hames	84	23	Heart disease	Hospital	No
Kevin Horton	87	14	Dementia	Hospital	No
Beatrice Irwin	83	22	Lung cancer	Facility	Yes
Greg Masters	84	20	Heart attack, CHF, Stroke, Liver Damage	Inpatient Hospice Facility	Yes
Felicity Matthews	96	54	Heart disease	Facility	Yes
Naomi Pullings	89	17	Stroke	NA (still living)	Yes
Catherine Rollins	86	21	COPD, Parkinson's	NA (still living)	Yes
Madeline Smith	90	20	COPD	Facility	Yes
Erving Tines	84	3	Unknown	Nursing Home	No
Willis Tines	83	5	Unknown	Hospital	No
Rebecca Thomas	91	66	Heart disease	Facility	Yes
Barbara Williams	81	58	Diabetes	Facility	Yes

Profiles of Death and Dying

In order to introduce the process of death and dying in AL, I present six case examples of residents selected from the 18 residents presented in Table 3.2. These cases illustrate a range of experiences regarding death and dying in the Purple Home and serve to highlight the varying components of these processes, which include: functional decline, social definition of the dying status, hospice use, communication about death and dying, circumstances around and handling of the death event, and responses to death and dying from residents, staff, and family members. The cases provide information about the residents' backgrounds, their pathways to AL, their health conditions, and, for some, the details of their decline and/or eventual death. Along with other residents named in Table 3.2, I will draw on these cases throughout the remainder of the chapter in my examination of the processes associated with death and dying in AL, and the respective sources of variation.

Madeline Smith

Madeline was a 90-year-old widow who was born and raised on a farm in rural North Carolina. She later moved to the town where the facility was located to be near her only daughter, but prior to moving, she had lived by herself for 12 years after her husband's death. Madeline first lived in the independent building for three years, but after falling and breaking her leg, she moved to the Azalea building in AL. Madeline often said that she was closest to her 15-year-old dog, Pete, who lived with her daughter after Madeline could no longer keep him. Madeline's daughter sometimes brought Pete to the facility for a visit, but not as much as Madeline would have liked and she missed him terribly. Madeline's relationship with her daughter was somewhat strained since her daughter remarried and she was not fond of her son-in-law.

At the beginning of the study period in June 2008, Madeline already was physically frail. She was in a wheelchair and having to use oxygen periodically. She had been told by her doctor that she would never walk again, but she was still hopeful of improvement and received physical therapy from a home health agency in an effort to regain mobility of her legs. Madeline had periods of confusion but was able to carry on a coherent conversation. She required staff assistance taking her medicine, bathing, walking, and getting in and out of bed.

Madeline seemed depressed and lonely and often said she wanted to return to her home in North Carolina. She described herself as a “loner” and often stayed in her room but was friendly with her tablemates and even placed one of them (Barbara Williams) in her social network.

In early December 2008, Madeline went to the hospital for a few days because she was having trouble breathing. Madeline then began to steadily decline. By mid-December, she had been placed on hospice and was being given a morphine pill for pain every 12 hours. A researcher reported in field notes on January 8th that Madeline was no longer coming to the dining room for meals and was having her food pureed. Towards the end of January, researchers first noted that Madeline yelled out and moaned at different times of the day. She often could be heard by other residents, since her room was adjacent to the dining room. A researcher reported in field notes on January 22nd:

I sat in the back corner, near Madeline Smith’s room. I suddenly heard her screaming for help, hollering and moaning, ‘Help! Help! My legs!!’

Though Madeline’s yelling didn’t seem to bother the residents, staff often commented about Madeline’s outbursts. One caregiver reported that she thought that Madeline was “seeking salvation,” which she believed was characteristic of dying people. In her view, people who “have

been saved” die peacefully. Another caregiver said that she thought that Madeline’s fitful death meant she was harboring a “deep, dark secret.”

Madeline Smith died on February 6, 2009 at the facility. According to a caregiver, her death occurred only moments after the son-in-law she did not favor left the building. Madeline’s obituary in the local newspaper reported that she would be cremated and her cremains would be buried at a later date in her hometown next to her husband of 51 years. Madeline’s wish was for her ashes to be placed in the same urn as her beloved dog and burial would be delayed until his death.

Barbara Williams

Barbara Williams, age 81, lived in the town where the Purple Home was located all of her life and her former home was nearby. She moved to the facility on July 5, 2004.

Barbara was a widow. Although her only child, a son, died as an infant, she raised her sister’s children, Justin, Warren, and Wendy. She was close to her nieces and nephews, but was especially close to Justin, who visited Barbara almost daily, took her out to lunch and to her doctors’ appointments, and was considered her “primary caregiver” by the staff. Her niece, Wendy, visited occasionally, but, according to Justin, Wendy had a drug problem and often took Barbara’s pain pills before she lived at the facility.

Barbara was well loved by both staff and fellow residents because of her kind nature; staff and residents described her as being “very sweet.” She often told staff how much she appreciated and loved them, and two morning staff persons, Krystal and Tammi, had a special relationship with her. Barbara attended entertainment-type activities, but enjoyed spending much of her time sitting in the sun on her patio or going to Krystal’s with Justin, her nephew. She had good relationships with her tablemates.

At the beginning of the study, Barbara was in a wheelchair and often experienced erratic changes in her blood sugar and vision problems because of her diabetes. Barbara went to the hospital in late December, 2008 for multiple eye surgeries. In the middle of January, her family enrolled her in hospice because of renal failure. As Barbara declined, she continued to have episodes of fluctuating blood sugar, but she still was able to enjoy her favorite activities.

Barbara was not afraid of death and had told Justin that she was ready to see her husband, child, siblings, and parents “on the other side.” Barbara once commented to a researcher that she did not know why she was still alive and guessed it was because the “Lord was not ready for her yet.” Justin began therapy several years ago in anticipation of Barbara’s death. The therapy had enabled him to have some insightful and meaningful conversations with Barbara about her impending death.

On May 6, 2009, Barbara died at the facility with her niece, Wendy, by her side. A researcher who was in the facility at the time of her death reported in field notes what happened that morning soon after Barbara’s death:

I walked toward the dining room and I saw that Barbara Williams’ nephew, Warren, and his sister were sitting outside Barbara’s room. Deb [a privately-hired sitter] was standing next to Krystal and another member of the care staff that I didn’t know. They were all speaking in hushed tones and Krystal informed me that Barbara Williams had just passed away just about 45 minutes ago. Krystal began to tear up as she told me the sad news which, in turn, made me cry. I stepped outside for a couple minutes to compose myself. The staff was visibly upset and shaken by the incident. It was no secret that Barbara was one of their favorites. When I returned [from the other building], Krystal said that Barbara began a drastic decline on Monday, but they didn’t expect her to go so quickly.

Barbara's niece was at her side the moment she passed. A representative from the funeral parlor was talking to the family, and Barbara's body was on a stretcher in a body bag in her room. Meanwhile, Dan Jones, another resident, was trying to come out of his room and swap out his old phone book for a new one. The staff was very concerned about getting him out of the dining room so he wouldn't have to witness the event. He seemed pretty clueless about what was taking place.

Later during lunch, the researcher made further observations of the response in the facility to Barbara's death:

The residents started filtering in for lunch and I was curious to see how quickly the news spread about Barbara's death. I moved over to talk to Madison Grimes. She didn't mention anything right off the bat, but shortly after I sat down, Linda walked by and said, "I'm so sorry about your friend." Mrs. Grimes said, "It's okay, I'm happy for her. She wanted to go!" Mrs. Grimes said that Krystal had come in just after she passed away and let her know what had happened. Word seemed to have gotten around – a lot of the residents entered the dining room already knowing the news. Justin then came walking in the back door wearing sunglasses – it was obvious that he had been crying. He walked over to our table and everyone expressed their sympathy. Mrs. Madison gave him a hug and told him that Barbara was "her first friend here." Justin said that he knew that and he was sorry for her loss, too. Justin left and went into Barbara's room. Suddenly, a woman from the administrative office [not sure who it was] and Jessica, the front desk girl, called everyone's attention and the woman said, "We lost one of our beloved residents today, and Jessica is going to sing a song in Barbara's honor." Jessica sang a really lovely song and Krystal was facing the back wall, crying. Patty [a resident] was wiping tears from her

face – it was really, really touching. After the song, I excused myself from the table and said goodbye to everyone. Patty and Linda [residents] said that they were very upset about the news because they thought Barbara was “so sweet.”

Barabara’s funeral was held two days after her death in the town where she had lived her entire life.

Walter Hames

Walter Hames and his wife Rita moved to the Azalea building of the Purple Home on January 10, 2007, from the independent apartments. Both had been long time residents and school teachers in the local community and had been married for 60 years. One of their two daughters lived nearby and visited frequently and sometimes brought her two golden retrievers. Walter and Rita had five grandchildren and one great-grandchild. They regularly attended a local Baptist church and had friends there.

Walter had a heart condition and participated in a cardiac rehab program twice weekly but was relatively independent and still drove locally. He was the caregiver for Rita, who had dementia. Except for being hospitalized at the end of August, 2008 because of a bout with diarrhea, Walter’s health seemed stable, but on December 21st, Walter suddenly died. He was 84. His funeral service was the following week at the Baptist church they attended.

After Walter’s death, Rita’s dementia seemed to worsen, and she even showed signs of not understanding that Walter was dead. On February 18th, a researcher recorded in field notes a conversation between Rita and a visitor in which Rita informed the visitor that Walter “hadn’t passed away – he was just out.” When the woman said to Rita, “Well, where did he go?,” Rita became even more confused and frustrated and began to cry.

For some time after Walter's death, Rita often stayed in her room, not even coming out to meals. According to field notes, almost two months after Walter died, a researcher encouraged Rita to come to an activity and reported that Rita looked like she had been crying. Rita told the researcher she was "just missing Walter." On April 10th, about four months after Walter's death, it was documented in field notes that a caregiver noted that Rita seemed more confused and that her family was visiting more frequently. At the end of the study period, field notes continued to document Rita's grief, including instances of crying when she talked about Walter. Rita often spoke of the nature of their marriage, which she deemed "more special" than experienced by other residents. By then Walter's death appeared to be a reality for Rita, as evidenced by comments to a researcher such as, "He died, you know."

Elizabeth Cummings

Elizabeth moved from her home to the Azalea building on March 30, 2008 with her husband, Henry. Elizabeth and Henry had been married for 61 years and met in church. Henry's family had been in Georgia since the 1700's. They had one son who worked in the nearby town and often stopped by to visit his parents.

Elizabeth and Henry moved to the facility because Henry needed assistance in caring for his wife, who at the beginning of the study period was confined to a wheelchair as a result of numerous falls. Elizabeth also was obese, had diabetes and some dementia, and experienced difficulty communicating and had had a stroke in the past. Henry on the other hand was independent and still able to drive.

Though the staff provided Elizabeth's personal care, Henry pushed Elizabeth around the facility and to and from meals and cut up her food. Elizabeth was often demanding of Henry's time and attention. According to field notes on October 31st, a researcher recorded that a staff

member had told her that Elizabeth was jealous of her and that Elizabeth would “cuss her out” if she “messed with her man.” A resident also commented on how Elizabeth often called out to Henry for help and then verbally abused him for how he helped her. In an interview with Henry, Henry said that he was dissatisfied with his life as a whole and didn’t like “this type of life.” Henry’s care giving responsibilities, as well as Elizabeth’s verbal abuse, likely contributed to his dissatisfaction.

Elizabeth and Henry spent the majority of time in their room, though Henry often sought respite at IHOP or Starbucks. Neither Elizabeth nor Henry attended any facility activities; they only left their rooms for meals and when Henry pushed Elizabeth around the grounds. Elizabeth did not have any close relationships with other residents and mainly interacted only with Henry and her tablemate, Ingrid Black.

At the end of December, Elizabeth broke both of her feet from using her recliner and was transferred to the nursing home next-door. Henry visited her everyday and fed her breakfast, lunch, and dinner. Elizabeth returned to the facility in the middle of March. Gangrene then developed in her leg, and she was hospitalized and her leg was amputated around the first of April. Shortly after, Elizabeth was put on inpatient hospice because the gangrene was still spreading throughout her body. Henry regularly visited her in the hospital. Elizabeth died in the hospital on April 12th. By the time of her funeral on the 15th Henry had already moved from the facility to the home of his son.

Field notes from a visit made by Henry to the facility less than a month after Elizabeth’s death suggested that Henry was adjusting well to the loss of his wife. According to field notes on May 7th:

Deb[a privately-hired sitter] told me that Mr. Cummings had come to visit the facility earlier and that he “hunted” her down at the beauty parlor. She said that he gave her and Alberta a hug. She said that he looked good and had apparently lost some weight. She said that he was in good spirits but said that it was hard after losing his wife. Deb said that he was living with his son and daughter-in-law. Mr. Cummings told her that he had just eaten at the Cracker Barrel and that he had gone to Starbucks the day before. Deb said that he enjoyed going to Starbucks. She said that he liked to go there and read. Mr. Cummings has apparently started reading a new book.

Catherine Rollins

Catherine Rollins was an 86-year-old widow who grew up on a farm in Georgia and was the youngest of 12 children. Catherine had previously lived in the independent apartments and moved to the Dogwood building in 2007.

Catherine described the hardships her family faced because they were poor and her father had died at a fairly young age. Catherine was able to put herself through a typing course and get an office job that allowed her to be out on her own. She later married and lived a comfortable lifestyle. Catherine was very religious and often spoke of how God helped her to get through the loss of her husband. Catherine had a nicely decorated room and always wore nice clothes and got her hair fixed until she started to decline.

Catherine never had any children of her own but had nieces and nephews “to love.” Her nieces and nephews gave her a great deal of support initially, but Catherine said the support and visits had gradually dwindled down. Her nephew helped Catherine manage her finances and usually took her to her hair appointments.

Catherine had Parkinson’s disease, and, at the beginning of the study period, she was using oxygen regularly because of chronic pulmonary disease (COPD). Though Catherine had

breakfast in the AL dining room, she had her other meals in the independent building. She attended entertainment-type of activities and got along well with both her tablemates from the independent and AL buildings. However, it was difficult for Catherine to socialize because of her limited mobility and lung function, and she did not have close friendships with other residents.

Catherine gradually declined during the study period and in March she was hospitalized for several days. After Catherine returned to the facility, she began eating all of her meals in the AL dining room. In April, Catherine went to the hospital again. On her return to the facility, she was on hospice and her family had hired a sitter who had previously cared for Catherine's sister and brother when they had been ill. Catherine's four-poster bed was replaced with a hospital bed, and Catherine's sitter brought Catherine's meals to her room. A researcher reported in field notes on April 15th:

Several of Catherine Rollins' family members were around today. I saw the man I had seen an earlier visit sitting in the common area and went up and introduced myself. He said he was a nephew. He said Catherine was feeling a little stronger today. He also said that hospice was putting in a hospital bed today. I wondered how Catherine would like that since she loved her pretty bed. In a little while he motioned to me that I could go see her. She was sitting in her chair but looked extremely thin and weak. Her hair was not groomed and she had the oxygen in her nose. She knew me though and held my hand and thanked me for coming.

Catherine's tablemates from AL often asked researchers about Catherine's condition and worried about her. One of her tablemates, Kathleen, said to a researcher, "Poor Catherine, she is having a hard time." In either August or September, Catherine went to a nearby hospice house

for a short period of time. Catherine currently is living at the facility and still is on hospice and has a sitter.

Greg Masters

Greg Masters was an 84-year-old widower who moved into the Azalea building on January 24, 2008. Greg had experienced a heart attack and a stroke and had significant liver damage. At the beginning of the study period, he was confined to a wheelchair. A researcher described him as “very frail looking with a very kind face” with a habit of repeatedly squinting and blinking his eyes, “as though he might have some vision or eye issues.” Greg had a friendly personality and was described as “very talkative” although his voice was weak.

Greg had two sons and a daughter and one son, Greg Jr., was very involved and visited almost daily; he also took his father to doctor’s appointments, ran errands for him, and helped him with his baths, shaving, and managing his money.

Though Greg spent a great deal of time in his room, Greg Jr. facilitated relationships between Greg and other residents during his regular visits. Greg Jr. also interacted with the other residents and sometimes had meals with Greg at his table. Greg got along well with his tablemate, Kevin Horton, who Greg affectionately referred to as his “little buddy. Kevin often worried about Greg when his health started declining. Greg also considered Joe Tyson a friend, and Joe often playfully teased Greg. Greg was also loved by staff; Krystal referred to Greg as “sweet.”

Despite Greg’s significant health problems, he often spoke of wanting to leave the facility and winning the lottery, which would enable him to build a house that he could live in with his granddaughter and great-granddaughter. In field notes dated August 4th, Greg expressed the desire to “drive and drive and get out of this place.”

Greg was hospitalized in late June for fluid buildup related to his liver damage. Around the first of September, Greg entered the ICU for kidney failure. Greg Jr. said that although the hospital recommended dialysis, the family decided not to subject Gregg to this treatment because Greg's wife had a bad experience with dialysis. On September 4th, Greg was transferred to the Loving Hands Hospice House. Greg Jr. did not always agree with Greg's doctors because he believed in a more natural regime of healing and gave Greg some homeopathic medicine while he was at the hospice facility. According to field notes on September 5th, Greg Jr. told a researcher that he did not think that his dad really understood what the hospice house was but rather thought he was in an extension of the hospital. Greg Jr. said he wanted to try and keep things positive and that he would eventually tell his dad the truth so he could tell him goodbye.

Greg died on September 12th, 2008 at the hospice house. It was never known whether or not Greg Jr. told his father why he was there. It was evident that Greg Jr. also was exhibiting death denial, which could have contributed to Greg's own denial of his terminal state. After Greg's death, Greg Jr. and his wife came by the facility to bring cookies and a thank you card to the staff expressing their gratitude for the great care they had given Greg.

Variation in the Dying Process: Dying Trajectories

I will use the term "dying trajectory" (Glaser & Strauss, 1968:6) to examine the varying experiences of residents regarding their socially defined course of dying—the period beginning when they are defined by self and others as in fact dying and ending with their death. In my analysis I examine the duration and shape of residents' dying trajectories. Duration denotes the time period of dying; shape refers to the slope of residents' decline as they approached death.

Duration and Shape

The dying trajectories of the 18 residents who were defined as dying and/or died during the study period varied in the duration and shape. Precise information is lacking about when the dying status was designated for nine of these 18 residents. For the remaining nine, duration ranged from one to seven months. Regarding shape, trajectories included those where the slope of decline toward death was gradual as well as those where the decline was rapid. The dying trajectories of some residents simply represented a continuation of the decline they experienced prior to assuming the dying status.

Rebecca Thomas (not profiled) illustrates a dying trajectory with a relatively long duration (four months) and a gradual slope. As indicated in table 3.2, Rebecca was 92 years old and had lived in the Dogwood building for five years when the study began. At that time, she already was quite frail, left her room only for meals, walked slowly with the aid of a walker, and was usually in a great deal of pain because of arthritis in her neck. Rebecca, however, did not consider herself to be dying, nor did others. Her status changed after a visit to the hospital in April, 2009 during which she underwent a diagnostic heart procedure that showed she had significant occlusion in a heart valve. At this time Rebecca's physician put her on hospice and estimated that she had four months to live. Rebecca continued to decline gradually while on hospice, though she still went to the dining room for meals when she was able. Rebecca had always prided herself in being independent, but it became more difficult for her to take care of herself. During the last weeks of her life, Rebecca never left her room; she began to retain water, causing her face to appear swollen. In August of 2009, four months after being put on hospice, Rebecca died at the Purple Home.

Barbara Williams (see profile), a resident who lived in the Azalea building, illustrates a dying trajectory similar to that of Rebecca in that it was characterized by a long duration and

gradual decline. Barbara at 81 years was younger than Rebecca. She had suffered from diabetes since she was a teenager and had mobility and vision problems as a result. Barbara had begun to decline and to experience fluctuating blood sugar and vision deficits before being designated as dying. In January of 2009, Barbara was put on hospice for renal failure, and, though she continued to decline, she still attended meals and some activities. Barbara died in May of 2009, almost five months after being put on hospice. Like Rebecca, she had lived at the Purple Home for five years.

Madeline Smith (see profile), who was 90 years old and lived in the Azalea building, like Rebecca and Barbara, experienced considerable decline before being designated as dying. The slope of Madeline's dying trajectory, however, was steeper. After Madeline was put on hospice in mid-December of 2008, she no longer was able to come to meals and all of her food had to be pureed. She died at the facility just two months later.

In contrast, other residents were relatively independent and healthy until they were diagnosed with a terminal illness. An example is Jim Bates (not profiled), age 88, who before his diagnosis of brain cancer, was living in the independent apartments with his wife, Gina, and was her primary caregiver. After Jim's diagnosis in March of 2009, the couple moved to the Dogwood building, and Jim began to receive hospice services. Jim declined rapidly and one week before his death in April of 2009 was transferred to an inpatient hospice unit where he died, only one month after he assumed the dying status and moved to AL.

Beatrice Irwin (not profiled) illustrates a similar dying trajectory to Jim but with a somewhat longer duration and more gradual slope. Prior to Beatrice's diagnosis of cancer, she had been active in the facility and the community and was physically independent. Beatrice was diagnosed with cancer in May of 2008 at age 83 and soon after began a course of chemotherapy.

After five months of treatment, Beatrice was told by her oncologist that the chemotherapy had not succeeded in preventing the spread of her cancer. At this point, Beatrice's was defined as dying by her physician, herself, and others around her, and she enrolled in hospice. About a month before her death, Beatrice became bedridden; she died in February of 2009, almost five months after beginning hospice care. Her tenure in the Purple Home was one month short of two years.

Two residents in the sample died suddenly, and thus had no specified period of dying prior to their deaths, i.e., no dying trajectory. One was Walter Hames, age 84, (see profile), who lived in the Azalea building and died unexpectedly of an apparent heart attack. The other was George Collins, also a resident of the Azalea building who died at age 97 of pneumonia, seven days after suffering from a broken hip resulting from a fall.

Factors that Influence Death and Dying Processes and Trajectories in AL

The principal factors that influence the trajectory (i.e., the duration and slope) of residents' dying trajectories are their unique health conditions and events and the point at which their dying status was socially defined. Both factors resulted in a variety of dying trajectories among the residents in my sample.

Health conditions and events. Different types of health conditions and events resulted in varying symptoms and had varying influences on the dying trajectories of residents. In general, data show that residents who had long-term chronic health conditions, such as COPD, diabetes, and congestive heart failure, experienced trajectories with longer duration and gradual slope. In the trajectories described above, Rebecca Thomas, Madeline Smith, and Barbara Williams all represent residents with chronic diseases that caused gradual and progressive decline. Catherine Rollins, whose trajectory is still continuing (see profile), illustrates a comparable trajectory.

The two residents in my sample, Jim Bates and Beatrice Irwin, who had cancer, experienced relatively shorter dying trajectories due to the more aggressive nature of the disease. These two residents varied in their trajectories as well because of the type of cancer each had. As mentioned earlier, Jim Bates' dying trajectory only lasted one month. Beatrice's dying designation was delayed by her election of treatment, and her trajectory was somewhat longer in duration than was Jim's.

Two residents, Walter Homes and George Collins, as noted above, experienced acute health events (cardiac arrest and pneumonia) that resulted in their sudden deaths. Although each had chronic conditions, they had not been given the designation of dying prior to their deaths.

Social definition of dying. The point at which dying was defined socially greatly affected the duration and the slope of a resident's dying trajectory. In the examples given above of those residents who experienced chronic disease with a long and progressive decline, the point of initiation of the dying status could be considered rather arbitrary. In these cases, duration of the dying trajectory ranged from one to seven months. Another example of a resident with similar progressive decline but with a much shorter dying trajectory is illustrated by Felicity Marshall. Felicity had lived in the Dogwood building for over four years when the study began in June of 2008. Felicity then was 96 years old, very thin and frail, and suffered from osteoporosis and heart disease. According to others in the home, Felicity had experienced considerable decline during earlier years, and our data show continued decline during the study period. By December of 2008, Felicity rarely left her room for meals. In early January, Felicity was transferred to the hospital, at which time a fellow resident who was a close friend, commented that Felicity was "out of it" and not herself. While at the hospital, Felicity was put on hospice. Felicity asked to return to the Purple home so that she could die "at home." She died the next morning, only one

day after her enrollment in hospice. Although Felicity was one of the oldest residents at the home and had been declining for some time, to her physician, family and even Felicity herself she was not *dying* until her hospitalization.

In some cases, a health event and/or medical diagnosis made the designation of the dying status more clear-cut. As mentioned earlier, Beatrice Irwin was defined as dying by her oncologist after her chemotherapy was unsuccessful and the cancer had continued to spread; Rebecca Thomas's dying status and estimated time of death was established after a heart diagnostic procedure.

Physicians played an important role in designating residents' dying status. In most cases, once a physician defined a resident as dying, the resident, their family, and the staff at the Purple Home shared this perception. For example, when Rebecca Thomas' physician told her that she had four months to live and put her on hospice, she, her daughter, and son-in-law immediately accepted and acknowledged her new status and communicated this information to others in the Dogwood building. Rebecca then was defined as dying by the staff and other residents. Rebecca was extremely pragmatic about her situation and commented to a researcher, "I guess that's what happens when you live to be 92."

In contrast, Greg Masters (see profile) failed to accept a dying status, despite the critical nature of his condition. At the beginning of the study period, Greg already had experienced a heart attack and stroke and had significant liver damage. Although Greg continued to decline and was hospitalized in June 2009 for several days as a result of fluid build up, he resisted thinking of himself as dying and often talked about moving out of the home on his own and building a house. Greg's health worsened considerably when he was admitted to the ICU in September of 2009 for kidney failure. At this point, Greg was defined as dying by a physician

and sent to an inpatient hospice facility. Even then, Greg's son denied Greg's dying designation and continued giving his father homeopathic medicine. Greg died eight days later.

Enrollment in the hospice program coincided with the designation of the dying status for all of the nine residents defined as dying. Hospice participation created visible signs to others in the home of a resident's dying status. When a resident participated in hospice, typically a hospice aide came to the home and assisted with the resident's care. This was the case with Naomi Pullings, who is 90 years old and lives in the Dogwood building. At the beginning of the study period, Naomi was energetic, played her harmonica, and was able to propel her wheel chair easily. However, as the study progressed, Naomi became weaker, and began having difficulty getting around. She ate little at meals and often fell asleep at the table. In early January of 2009 Naomi experienced a fall and later in the month was enrolled in hospice with a diagnosis of "failure to thrive." The aide's presence in the home communicated Naomi's hospice, and thus dying, status to other residents and to staff. Naomi fell again in March, and at the end of May, Naomi had a severe nose bleed and was transferred to the hospice facility. Although a staff member indicated that she did not think Naomi would return to the facility, she was back in a few days. Toward the end of the study period, Naomi regained some of her appetite and strength and ultimately was removed from the hospice program. Naomi was the only resident in the Purple Home to experience a *reversal* of the dying designation.

Individual, Family, and Facility Responses to the Dying Status and the Factors that Influence

Data show a variety of responses in the facility to a resident's dying status. These include: verbal communication of the information; changes in the physical environment; changes in the resident's care, health status, and appearance; and changes in the behaviors of residents and their family members.

Verbal Communication

In most cases information about a resident's dying status was verbally communicated after a resident was put on hospice. When Rebecca Thomas returned to the facility after the diagnosis of her terminal condition, her new status of dying was communicated by staff and Rebecca. A caregiver and housekeeper told researchers about Rebecca being on hospice. Rebecca also told a researcher about her prognosis and then later told her tablemates that she was on hospice and only had four months to live. Communication about dying also involved varying estimates of how long a resident had to live. For example, months after Beatrice Irwin had been placed on hospice, staff and residents communicated to researchers varying numbers of remaining months. Jessica, a caregiver, estimated six months, but then a week later, Beth, the housekeeper, specified three months. A month and a half later, a resident communicated that Beatrice had six months to live. Obviously such varying estimates are in part due to the difficulties surrounding predicting precise times of death, but they also likely are caused by miscommunication among the various parties.

There were also times when residents faced barriers to verbal communication regarding other residents' dying statuses because of facility policy, based on the Health Insurance Portability and Accountability Act (HIPPA), which prohibited staff from divulging residents' health-related information. For example, when Rebecca Thomas was sent to the hospital, her tablemate and friend, Faith Deakins, asked a staff member where Rebecca was when she did not show up for breakfast. When the staff member would not give Faith the requested information, Faith asked the volunteer who led the church service every Sunday morning. The volunteer was able to get the desired information (that Rebecca was in the hospital) from the staff person and then passed it on to Faith. Data show that on numerous occasions, staff refused to tell residents

about other residents' health conditions or dying statuses, but they usually provided the information to members of our research team. An example of this is depicted in the following passage in field notes:

When I walked into the Azalea building, lunch had already started. I saw Ana, a former employee, sitting at the table with Kevin Horton. I wondered where Greg Masters was. I sat down with them. Ana told me that Greg was in hospice and that he had about two days to live. She said this quietly so that Kevin Horton would not hear.

However, Tina Matthews, the Purple Home executive director, told a researcher in an interview that staff try to give residents an update about the status of a resident when he or she is sent to the hospital or put on hospice. Therefore, it is unclear what the specific stipulations were for communicating residents' conditions within the Purple Home. We also observed inconsistencies in how this and other policies were followed, and it is likely that informal policies sometimes differed from formal ones, depending on the situation.

Environmental Changes

Changes to the physical environment that occurred in response to a resident's decline also served to communicate information regarding a resident's dying status. A common environmental change was the arrival of medical equipment, especially hospital beds. During one visit, a researcher noticed workers unloading a hospital bed from a medical equipment van in the parking lot and moving the bed into Beatrice Irwin's room through her back patio door. Five of the nine residents enrolled in hospice had their traditional beds replaced with hospital beds. These institutional looking beds sometimes changed the appearance of a resident's room dramatically. For example, Catherine Rollins always prided herself on having an elegant room, and she loved her four-poster double bed, which matched her other bedroom furniture, and made

sure that it was made daily and spread with her beautiful quilt. When the beloved bed was replaced with a hospital bed, Catherine's room looked much less homelike even though more space was now available to provide care. Rebecca Thomas received not only a hospital bed after she was placed on hospice, but also a wheelchair and an oxygen machine. Rebecca complained that her new bed was not as comfortable as her old one had been.

Other environmental signs included the presence of hospice staff and sometimes changes to the resident as a result of the added care they provided. When Naomi Pullings went to meals, a hospice aide often accompanied her and her uniform and hospice nametag helped communicated to others, especially to other residents, that Naomi was dying. Before receiving hospice services, Naomi's hair often looked greasy and her clothes sometimes had stains on them. However, during one visit, a researcher noted that with the help of a hospice aide, Naomi's hair was brushed and she was nicely dressed in a matching pants suit. Her tablemates commented on her improved appearance.

In addition to hospice staff, Catherine Rollins' family hired a private sitter, Sandy, to provide extra care to Sandy. Sandy was observed daily delivering meals to Catherine's room and often stopped by Catherine's former table to communicate information about Catherine's status to her former tablemates.

Another significant environmental change in the home often was the absence of the resident. Some of the dying residents only came to meals occasionally, or stopped coming out of their rooms completely, especially as they declined further. Others were transferred at times to other care facilities.

Changes in Care and Behavior

After residents were defined as dying, they typically required more care. Because the Purple Home did not increase staffing levels when residents declined, the heavier care dying residents usually needed created an extra burden on facility staff. Although hospice staff assisted the residents with care during periodic visits, daily care was provided by the Purple Home staff. For example, in her final months Madeline Smith required assistance with feeding, and staff had to assume this task when Madeline's daughter was not available. This added task was particularly burdensome for staff because their meal time duties, which included taking orders and serving, already were considerable. Residents with sufficient financial resources could pay for additional care, as in the case of Catherine Rollins, who engaged a regular sitter to supplement care from facility staff.

The behaviors of family members also changed with changes in a resident's status. Staff reported that some family members visited more frequently once the resident was defined as dying, and researchers also observed changes in family visitation patterns. For example, at the beginning of the study period, Madeline Smith told researchers that her daughter rarely brought her dog, Pete, to visit her and she missed him terribly. After Madeline was put on hospice, Madeline's daughter increased her own and Pete's visits. Rebecca Thomas's daughter also was observed visiting her mother more frequently. However, with some residents, especially those without children, family visitation did not increase and even declined. Catherine Rollins, whose only family support comes from nieces and nephews, provides an example. Catherine reported to a researcher that her visits from family became less frequent after her condition worsened. When Catherine was put on hospice, researchers observed her nieces and nephews gathering at the

home while waiting for Catherine's hospital bed to arrive. After that time, researchers observed no further visits.

Family members varied in other behavioral and emotional responses to the dying knowledge. Barbara William's nephew, Justin, initially expressed fear at the thought of losing Barbara, but he subsequently went to a therapist to help prepare for her death. Although Justin did not want Barbara to die, he came to realize that her death was inevitable and that ultimately he would be able to move on with his life and pursue his own goals. In contrast, when Beatrice Irwin was defined as dying, her husband, Jacob, had great difficulty coping with her decline. Beatrice and Jacob's neighbor and friend, Savannah Smith, told a researcher that on one occasion, she had gone to their room and seen Jacob sitting on his sofa crying. Staff also observed his grief. The greater effect of the anticipated loss of a longtime spouse, compared to other types of family relationships, is not unexpected.

Residents varied in how they responded to their own dying statuses. The nature of the decline was a principal factor in this variation. Even after Barbara Williams was put on hospice, her condition was such that she was able to continue to attend activities and enjoy sitting on her back porch in nice weather. Other residents, though, because of weakness or pain, gave up typical activities and remained in their rooms.

Data revealed the attitudes of certain residents regarding being designated as dying. Barbara Williams told her nephew that she was ready to die and see her family "on the other side." Barbara's lack of fear regarding dying resulted from her strong religious faith and belief in an afterlife. Rebecca Thomas' reaction to learning she had only four months to live was one of acceptance of her fate. She told a researcher that she was "ready to go" anytime. Rebecca was

mainly concerned about whether she would be able to stay at the Purple Home and avoid going to a nursing home.

Data reveal numerous factors that influenced the way in which residents and their families and facility staff responded to residents' dying status. Individual-level factors included residents' religion, age, health condition, hospice use, room location, relationships with family, other residents, and staff, and marital status, as well as certain traits of family members. The main facility factors were the physical environment, which rendered the dying experiences of some residents more public, policy toward hospice use (discussed more fully in the following section), and staffing levels. Community factors such as AL staffing regulations, HIPPA, and hospice availability also influenced verbal communication regarding residents' conditions and changes within the AL environment related to the dying process.

Understanding Death and Dying in AL: The Role of Hospice Use

Hospice use played a significant role in the death and dying experience of the residents in my sample and was one approach to managing these processes in AL. As made evident in the previous sections, hospice use often coincided with the designation of the dying status and also influenced the way in which residents and their families experienced dying and affected the visibility of dying in the overall environment of the Purple Home. In this section I will examine in greater detail the use of hospice in the Purple Home and the outcomes of participation in this program for residents, their families, and the facility. In addition I will examine the influence of various individual-, facility-, and community-level factors on hospice use and its outcomes.

Description of Use

Eleven residents used hospice services during the study period. The length of time of service use ranged from one day to seven months. Services included assistance with ADLs, pain control, skilled nursing care, counseling regarding dying and death, and equipment provision.

Palliative care is one of the primary functions of hospice and many of the residents using hospice services had their pain symptoms controlled. As noted earlier, Madeline Smith was given a morphine pill every 12 hours. Hospice nurses visited periodically to help with various medical needs and provide skilled nursing services, which AL staff were not allowed to provide. Hospice also provided a bereavement coordinator, who offered grief counseling for residents and their families. This service was utilized by Barbara Williams' nephew Justin. In addition, hospice arranged for supportive equipment. As discussed earlier, a large portion of residents received hospital beds after starting hospice; Rebecca Thomas also received a wheelchair and an oxygen machine to help her breathe easier.

For residents receiving hospice services in the facility, hospice care aides usually visited three times a week to assist with bathing, dressing, and grooming. Rebecca Thomas' aide was scheduled to come on Mondays, Wednesdays, and Fridays to help Rebecca with her baths. Naomi Pullings' hospice aide assisted Naomi with bathing, dressing, and grooming and sometimes pushed Naomi in her wheelchair to meals and encouraged her to eat. Because the hospice program does not provide 24-hour care, these services only supplemented care provided by facility staff and, in some cases, family members or paid sitters.

As noted above, not all the residents enrolled in the hospice program received services at the Purple Home. Greg Masters was sent directly to an inpatient hospice facility after being in the ICU. Although Jim Bates received hospice services at the Purple Home for a month, he was admitted to an inpatient hospice facility a week before he died. Elizabeth Cummings was

enrolled in hospice during a hospital stay, only two days before she died. Other residents were transferred to an inpatient hospice facility on a short-term basis to control pain or because of an acute health event, such as Naomi Pullings' prolonged nosebleed.

Outcomes of Hospice Use in AL

Hospice use resulted in a variety of outcomes for dying residents and their families, other residents, facility staff, and the facility organization. Most outcomes were beneficial for all parties.

Outcomes for residents and their families. For eight of the residents in my sample, hospice use allowed them to remain in the facility until they died. As mentioned earlier, because Felicity Marshall had lived in the Dogwood building for over four years, she considered the Purple Home to be her home. It was very important to Felicity to die at "home" and hospice allowed her to fulfill her desire. Hospice also helped Rebecca Thomas avoid transfer to a nursing home and to die in her own room. Thus, hospice facilitated some residents' ability to age in place in AL.

Hospice also provided needed attention and care that some residents in my sample were lacking even before they were defined as dying. This situation is best illustrated by Naomi Pullings, who only had bimonthly visits from her son and sometimes was treated as an inconvenience by facility staff. After starting hospice, Naomi's care and appearance improved. The added attention from hospice aides also may have contributed to Naomi's improved health status and ultimate removal from the program. As noted above, a significant outcome for many of the residents on hospice was pain control and the ability to die more comfortably. Since Beatrice Irwin had an aggressive form of lung cancer, she likely experienced a great deal of pain.

Palliative care from hospice hopefully alleviated her suffering during her final five months and lessened her husband's emotional stress.

When residents were receiving hospice services at the facility, their dying experiences and deaths usually became more public to others. This is best illustrated with Madeline Smith who received hospice services for about one and a half months at the facility. Because Madeline's room was adjacent to the dining room, residents and staff could easily hear her yelling and moaning during her dying process. Though it was observed that many residents did not seem to notice her outbursts, her behavior was often a topic of conversation among staff.

Outcomes for the facility. As mentioned earlier, hospice care aides relieved some of the care burden of facility staff. Another outcome for the facility was that hospice allowed some residents to stay longer at the facility. The increased tenure of these residents resulted in the maintenance of the resident census and, thus, the continued fee revenue from the residents. As stated earlier, eight out of the eleven residents on hospice in my sample were able to stay at the facility until death.

Influences on Hospice Use and its Impact

A variety of individual-, facility-, and community-level factors influenced the nature of hospice use and the impact that hospice use had on residents and their families and the facility.

Individual-level factors. The nature of a resident's illness had a significant influence on the nature and impact of hospice use. Obviously, residents who experienced acute health events leading to a sudden death did not receive hospice services. Rather, residents with long-term chronic health conditions were the main beneficiaries of the program. For example, Rebecca Thomas' heart disease and diagnosis of an occlusion in her heart valve led her physician to certify her for hospice. Her condition influenced the duration and slope of her dying trajectory,

and thus the nature and duration of her hospice use. The cancer conditions of Beatrice Irwin and Jim Bates and the diabetes of Barbara Williams had similar influences.

The nature of the health condition as well as the type of care needs each resident required also influenced where hospice services were received. Madeline Smith was able to receive hospice services at the Purple Home during her entire dying process because her pain medication could be administered easily by facility staff and she had no acute care needs. However, seven of the eleven residents on hospice had care needs that exceeded what the facility could provide on at least one or more occasion. For example, Elizabeth Cummings, who needed intravenous antibiotics to control the spread of gangrene, received hospice services in a hospital. In contrast, other residents, such as Naomi Pullings, received the bulk of hospice services at the facility but required temporary care for acute needs in a hospice facility. Another example was Edith Burchfield, who was 88 years old and experienced chronic and excruciating pain from shingles. Because Edith's pain could not be controlled in the facility, she required temporary inpatient hospice care. It also is likely that the fact that Edith shared an apartment with her sister Marie influenced her transfer because of the significant stress Marie experienced while observing Edith's pain.

Resident and family awareness and sanction of hospice also was necessary for its use. Lack of knowledge about hospice use was illustrated by Edith Burchfield and her sister, Marie. During a visit, a researcher commented to Marie that Edith might benefit from the palliative care offered by hospice and that their doctor could possibly enroll her in the program. Marie told the researcher that she thought hospice was allowed only in nursing homes, not ALFs. Edith subsequently enrolled in hospice, but she died after only one and a half month's use. With earlier

enrollment, Edith might have had her pain controlled sooner, which also might have reduced Marie's emotional stress.

Some residents and their families did not consider using hospice services because the resident was not yet defined as dying. Such was the case with Felicity Matthews, who although she had been gradually declining for some time, was enrolled in hospice just one day before she died. Felicity's case illustrates the subjective nature of the dying status. Another example of this subjectivity is Naomi Pullings, who although defined as dying by her physician, subsequently improved sufficiently to have her status redefined.

Another example of how denial of the dying status delayed hospice use is provided by Greg Masters. As described in his case example, both Greg and his son resisted acknowledging the severity of Greg's condition even after Greg was enrolled in hospice a week before he died of liver failure. With earlier acceptance of the dying status, Greg would have received hospice services longer and possibly had a more comfortable dying course.

Facility-level factors. Facility sanction of hospice use also was an important influence. When asked in her interview about the possibility of hospice use in the Purple Home, the executive director, Tina Matthews, replied:

Yes, absolutely, absolutely. We've had people go through end stage cancer and pass here all the time. The only time they wouldn't [stay] is say when they were having difficulty swallowing and they needed suctioning or something like that that they needed to be in an inpatient hospice situation or maybe they needed some IV meds instead of taking Raxinol or something orally or they needed a morphine push or something, anything like that that we can't do, then they would need to go to inpatient hospice, but other than that we've had a lot of people, cancer, different forms of cancer...

Therefore, residents were allowed to receive hospice services at the home, but facility policies (in accordance with state AL regulations) prohibited them from receiving skilled medical care, such as IV medication or suctioning, there. An example of a facility resident in that category was Elizabeth Cummings, who was transferred to the hospital in order to receive aggressive treatment for her gangrene.

A final facility-level factor that likely affected hospice use and its impact at the Purple Home was the home's continued use of the minimum staffing levels required by state regulation (1 staff person per 15 residents during day time and 1 per 25 at night) even with increased care needs of residents. This practice likely fostered the facility's use of hospice, as well as increased the benefits to facility staff of the intermittent help from hospice aides.

Community-level factors. Several community-level factors influenced the use of hospice at the facility. A key factor was state AL regulations, which govern how hospice is used in ALFs and thus influence facility policy. AL regulations allow hospice use, but if a resident becomes bedridden, the facility must apply for a waiver to provide the additional care required for this type of resident.

An equally important community-level factor that promoted the use of hospice at the home was the availability of Medicare, which reimburses the full cost of hospice care as long as a physician estimates that the recipient has six months or less to live. The recipient, though, may be responsible for paying no more than \$5 per prescription and is required to pay five percent of the cost for inpatient respite care if it is needed. Therefore, hospice could be used without expense to facility and only possibly a minimal cost to the resident.

Another community-level factor influencing hospice use was the proximity of the local hospice agency, "Loving Hands," which was located less than a block from the Purple Home.

This hospice agency also had an inpatient hospice unit, often referred to as a “hospice house,” which made it convenient for family members to visit residents. Although we were not aware of which hospice agency each of the eleven residents used, we did know that eight residents used Loving Hands Hospice.

The Death Event and the Factors Influencing

A key component of the death and dying processes in AL is the actual death event. Out of the 18 residents in my sample, 16 died during the study period (see Table 3.2). In this section, I will explore the varying situations surrounding these deaths, including: where deaths occurred; who was present; the sequence of events surrounding the death; the communication, or lack of communication, of information about the death; and the responses to death from residents, family members and facility staff. I also will examine the various factors that influence each of these processes. Because researchers usually were not present at the time of residents’ deaths, little precise data are available about the events that occurred at the time of death.

Situations Surrounding the Death Event

Data reveal five different locations where residents’ deaths occurred: the resident’s room in the facility (6); an ambulance in the facility parking lot (1); the nursing home adjacent to the facility (2); an inpatient hospice facility (2); and a hospital (5).

The most complete information is available about the death of Barbara Williams because two researchers arrived at the facility soon after she died (see profile). Barbara died in her room with her niece, Wendy, by her side. Shortly after her death, Barbara’s nephew, Warren, Wendy, and other family members gathered in Barbara’s room to meet with a representative from the funeral home while Barbara’s body lay on a stretcher in a body bag. Although researchers did not observe the actual removal of Barbara’s body, data indicate it was removed only moments

after the family meeting. Other family members were seen later on Barbara's patio. Although some residents seemed unaware of what was going on, news of Barbara's death traveled rapidly through those present in the facility: administrative and care staff and many residents.

Data also show that other residents were with family members at the time of their deaths. Beatrice Irwin's husband, Jacob was with her when she died at 12:30 a.m. Jacob told researchers after her death that she had been non-responsive for the last two weeks of her life.

In at least two cases residents were attended only by medical staff at the times of their deaths. The following field notes passage from observations at the hospital on September 15th, 2008 describes Kevin Horton's death:

When I entered the room, I told Mr. Horton's daughter-in-law that I was sorry to hear of Mr. Horton's death. I told her that I couldn't believe that he had died. She asked me to sit down. She told me that she was surprised by his death. I asked her what happened and she told me that he aspirated. She explained that she had gone by the hospital on Monday to see how he was doing and that when she got there she could see/hear people in Mr. Horton's room. She decided to stay outside of his room until they were finished working with him. She said she could hear him talking to the hospital employees in his room. A few minutes later, an employee came out and told her that Mr. Horton was dying and that she should call other family members. The daughter-in-law called her husband and told him that Mr. Horton was dying. A few minutes after she hung up, another employee came out of his room, hugged her, and told her that she was sorry. The daughter in law seemed to think this gesture was odd. A few minutes after that another employee came out, told her that she was sorry and explained that "they" had done everything they could for Mr. Horton. The daughter-in-law asked the employee what she meant by that statement and

the employee explained that Mr. Horton had just died. The employee said that the daughter-in-law could spend as much time as she needed with his body. The daughter-in-law went in to this room to see him one last time and then left the building.

Because Edith Burchfield passed away in the ambulance in the facility parking lot, Emergency Medical Transporters (EMTs) were the only ones present at her death. Edith's sister, Marie, was not aware of Edith's death until she arrived at the hospital, where hospice staff informed her that Edith had died.

We are lacking information regarding the specifics of body removal after residents died at the facility. However, after Barbara William's death, Christina, a caregiver, told a researcher that the facility does an "excellent job of doing it [removing the body] discreetly and fast." However, the researcher observed that the physical design of the facility makes it difficult to remove bodies in a private manner because all of the residents' rooms are situated around the dining room or other common areas. On another facility visit, Deb, a daily sitter for one of the residents, told a researcher that a body typically is taken out through the back door of the resident's room. If, for some reason, this strategy is not possible, the body is taken out through the common areas uncovered, to give the impression that the resident is just being transported to the hospital.

As noted in previous sections, health conditions and hospice use were the main factors that influenced how and where residents' deaths occurred. The supportive services provided by hospice significantly affected residents' ability to die in the Purple Home.

Communication of the Death Event

During the study period, our research team observed that there was no formal mechanism for communication of the death event for the majority of resident deaths. Rather, data indicate

that the primary means of information flow was through “word of mouth” among staff, residents and residents’ family members. News traveled more quickly when residents were neighbors or friends. For example, when Beatrice Irwin died, Savannah Smith knew immediately of her death because she and Beatrice were neighbors and friends. Felicity Matthews’ daughter-in-law went to Rebecca Thomas’ room and told her about Felicity’s death immediately after it happened because Rebecca was Felicity’s close friend and tablemate.

Data indicate that when a death occurred at the facility, especially during waking hours, word spread fast because of the visibility of certain events. The following passage, recorded in field notes on May 9th, 2009 describes information flow regarding Barbara Williams’ death:

Linda [a resident] told me that Barbara Williams died yesterday around 8:15 a.m. Linda said that she was at breakfast and saw Barbara’s niece walking out of Barbara’s door crying. A few minutes later, the staff came to Betty’s room followed by Tim Gaylord [Director of Resident Services]. A little bit later Barbara’s body was removed from the building. Linda told this story as a matter of fact. No one else made any comments about the death of Barbara Williams. I asked Linda if she had seen Justin, Barbara Williams’ nephew, and she said that she saw him go into Barbara’s room to get some pictures. I am assuming that he was getting pictures for the funeral.

Although Barbara’s and other residents’ deaths occurred in house, residents’ utilization of hospice also may have influenced the lack of awareness among residents about the deaths of fellow residents. With hospice, a nurse from the agency is allowed to make the pronouncement of death. Without hospice, the facility must summon emergency and law enforcement personnel, creating much more disruption in the environment. One resident whose room is located on the parking lot side of the building told researchers that she always sees the flashing red lights of

emergency vehicles through her blinds, even in the middle of the night. On the morning after one such event this resident asked a researcher if she knew who had been the reason for the summons.

The out of the ordinary presence of family members in the facility in some cases also provided indicators that a death had occurred. As mentioned earlier, Barbara Williams' relatives were observed coming and going on the morning of her death by residents having breakfast in the dining area, located adjacent to Barbara's room. Even when residents' deaths occurred out of the facility, family members often came to the resident's room soon after the death, providing a visible clue of the death event. This happened in the case of George Collins, whose daughter visited the home on the day of George's death and was observed talking to some of George's former friends. Although these residents may have known of his death, the daughter provided additional information.

The Purple Home allowed families of deceased resident to utilize facility common areas when needed. According to the following passage from field notes on August 14th, 2008:

I arrived at 12:30 and went directly to the Dogwood building. As I walked in the back door, I saw a large group of people in the TV room. The doors were closed and Willis Tines was in there with them. I wondered if Mr. Tines had died. Jessica told me in a little while that he had died this morning. During lunch I saw Mrs. Tines go back to her room. Family members went in and out during my visit.

In a few instances, staff told residents individually about the death of a close friend or tablemate. For example, when Barbara Williams died, a caregiver also informed her friend and tablemate, Madison Grimes, immediately after Barbara's death. Madison had often looked out for Barbara and read her the menu at meals each day.

As with information about residents' health conditions, data indicate that staff communicated information about death events more freely to researchers than to residents. Researchers usually found out about deaths during weekly visits to the facility, but when Greg Masters died, a caregiver from the Azalea building called a researcher to notify her of his death.

Sometimes residents told researchers about a fellow resident's death. Usually this information was communicated by a resident who had been close to the deceased. For example, Mandy Cables, neighbor, tablemate, and close friends with Jim and Gina Bates, informed researchers about Jim's death.

Residents who read the local newspaper typically learned about fellow residents' deaths through reading the daily obituaries. Wilma Bowen, a resident in the Dogwood building who subscribed to the paper, told a researcher that she often found out about residents' deaths in this way. Out of the 16 residents who died, 12 had obituaries in the local newspaper. These typically were cases where either residents or their family members were long-time residents of the local community. The obituary of Felicity Matthews, who lived most of her life in another area of the state, appeared in the newspaper of her hometown.

For at least two of the residents who died, Elizabeth Cummings and Willis Tines, flyers with information about times, locations, and dates of funeral services and visitations were posted on the wall above the counter of the nurses' station. These flyers were positioned in a way that made them difficult for residents to view.

On rare occasions, a residents' death was announced in the dining room. After Greg Masters died, Krystal, a caregiver, told a researcher that they announced his death to the other residents during a meal. Greg's death most likely was announced because he was well-liked by staff and other residents. Greg also was known by most residents owing to the fact that he spent a

lot of his time outside of his room in the dining area and he was one of the few males who lived in the Azalea building. However, Deb, a sitter, also told a researcher that a caregiver was fired for announcing Greg's death because communication of such information was against facility policy. The firing of the caregiver, however, was not verified by researchers.

A member of our research team also witnessed a public announcement of Barbara Williams' death (see profile). In this instance an administrative staff person made the announcement during lunch in the dining room of the Azalea building and then Jessica, the receptionist for the facility, sang a religious song in Barbara's honor. Therefore, it is unclear whether the Purple Home actually had a formal policy that prohibited staff from announcing resident deaths to other residents. Barbara's death was most likely publicly acknowledged because of her long tenure (five years) at the home and because she was well liked by staff and residents. As mentioned in her profile, Barbara had a kind nature, interacted often with others, and was described as "the sweetest resident here" by Patty Felton, a fellow resident. Barbara had close relationships with some of the staff and often told them how much she loved and appreciated them.

Similar to communication about residents' dying conditions, however, more subtle clues in the Purple Home's environment sometimes served to communicate death information. These included funeral arrangements, plants, or other tokens of appreciation donated to the facility by the deceased's family members. After Beatrice Irwin's funeral, several floral arrangements and plants, which were given by Beatrice's husband, Jacob, were displayed in the Dogwood dining room and common areas. A few days after the death of Greg Masters, his son and daughter-in-law visited the facility and brought a plate of cookies for the staff and residents. They also thanked staff in a card, as reported in field notes recorded on October 19th, 2008:

In the nurse's station I saw a thank you card pinned up on the bulletin board. It was a card from Greg Masters' family. It was signed by Greg, Jr. and his wife. It thanked the staff for doing nice things for Mr. Masters like cutting up Mr. Masters' food and rubbing his back while they cared for him.

Felicity Marshall's son, Brian, sent flowers to the staff expressing his gratitude to the staff for giving good care to his mother while she was living at the Purple Home.

The absence of the deceased resident at meals and activities and the clearing out or repainting of a newly vacated room also served as subtle means of communication. More than two weeks after Madeline Smith died, a researcher observed that other residents only responded to her death when they saw maintenance workers painting and refurbishing her room. On another occasion, a researcher commented in field notes that a volunteer from the activities department had stopped by Madeline's room after her death and, finding the room empty, simply thought Madeline had gone out, completely unaware that she had died. Possibly the lack of knowledge about Madeline's death related to the long period she was confined to her room prior to her death, as well as her tendency to be a "loner." In another case, long after the death of George Collins, Wilma Bowen noticed he was not at poker and asked about his whereabouts.

Data also indicated an absence of direct communication about a resident's death. In no cases was information about deaths posted in a public location, and as noted earlier, no formal mechanism of communication existed.

As with residents' responses to death, dementia affected residents' ability to retain knowledge about residents' deaths even if they had been told, sometimes more than once, about the event. Thus, death information often had to be re-communicated. One example was Rita Hames, whose dementia impeded her ability to retain the knowledge of her husband's death.

Another case was Wilma Bowen, who freely admitted that she continued to forget that George Collins was dead, even with constant reminders from a more alert tablemate. Another example was Louise Bennett, whose good friends, both members of a couple, had passed away after being transferred to a nursing home. Louise's lack of knowledge about the deaths, caused by her dementia, resulted in ongoing stress to her. She told researchers on more than one occasion that she did not know what happened and once even reported that they had been "executed." Louise had not been permitted to attend her friends' funeral, for fear the event would upset her, which may have contributed to her continuing stress.

Death and Dying Processes: Outcomes of Death

Another important component of death and dying processes in AL relates to the actual outcome, or response to a given resident's passing. In this section, I will explore the effect of residents' deaths on the facility's social environment, including the varied responses found among fellow residents, family members, and facility staff. The nature and degree of response (or lack of) was influenced by multiple factors relating to the residents who died and to others in their social worlds.

Personal Responses

For the most part, personal responses to the death of residents depended on the nature of the relationship the deceased resident had with other persons in their social world. That is, the closer the relationship, the greater the loss experienced. Relationships in turn were influenced by multiple other factors, some of which will be noted in the following discussion.

Significant grief was observed only by residents who also were family members of the residents who died—three spouses and in one case, a sibling. After Edith Burchfield died, her sister, Marie, was extremely sad and expressed to researchers that she did not know how to "let

Edith go” or how she could get along without her. The main factor that influenced Marie’s response to Edith’s death was their close and mutually supportive relationship. As mentioned above, Edith and Marie were not only sisters, but they were also roommates and extremely dependent on one another. In addition, Edith had no other close relatives nearby.

Other examples of deep sadness were found among remaining spouses. After Rita Hames lost her husband, Walter, she often was observed crying and sometimes did not leave her room for meals. Rita also spoke often of how much she missed Walter and about how wonderful their marriage of 60 years had been. At the Purple Home the couple usually kept to themselves, and Rita had not developed any close ties with her fellow residents. Rita’s dementia also affected her response to Walter’s death. Sometimes she forgot that he was dead, instead, thinking he had just temporarily left the facility. In addition, because Walter had been her primary caregiver, she was left to get through each day on her own. Similar loss was observed with Beatrice Irwin’s husband, Jacob. After Beatrice’s death, Jacob began eating breakfast in the AL dining room rather than in the dining room on the independent side, which is where he and Beatrice typically had eaten their meals before she became bedridden. A researcher overheard Jessica, a caregiver, telling another caregiver that while Jacob was in his room, he often kept the lights off, a behavior Jessica thought was a sign of depression.

In addition to dementia, other factors appeared to affect the response of residents to the death of a spouse. Gender likely contributed to Jacob Irwin’s tendency to keep to himself after Beatrice’s death. Savannah Smith, Jacob’s neighbor, commented to a researcher that she wondered if Jacob thought all the women may be “after him” now that his wife was gone. Jacob sat at a table by himself at breakfast reading his paper, an act possibly intended to discourage resident interaction. Data indicate that when Beatrice was well, both of them had been active in

facility life. In contrast, Gina Bates, more quickly became integrated into the facility social world. Gina's behavior likely was influenced by her outgoing, friendly personality and by her friendship with her neighbor, Mandy Cables. Family members also tried to temper the effect of parents' loss with additional visits. Rita Hames' daughters and grandchildren made more frequent visits after Walter's death.

In non-family cases, residents' responses to death also were influenced by former relationships. Residents who had been friends, and often tablemates, of the deceased resident usually expressed sadness and loss on learning of a death, but not to the degree noted in the cases above. For example, when Felicity Marshall died, two of her tablemates told researchers on multiple occasions how they missed Felicity. Another resident, Linda Bates explained the effect of Greg Masters' death on her and other residents:

Oh yeah, I think everybody was just, was sad about it and said how we're going to miss him and how he was, you know, and as I say, I took the therapy with him three times a week and I was going to miss him in our little classes we used to have. But everybody said he was so quiet and everything, but you get him started on stories and his mouth would just go ninety miles an hour, just telling you things.

Greg Masters was one of the few male residents in the Azalea building and got along well with everyone.

An example of more extreme grief over the death of fellow residents was the case of Louise Bennett, noted above. Louise had been extremely close to both members of the couple who died. According to the beautician in the home, they had lived together in the independent building and had "done everything together." Sometimes Louise would talk about the couple and

according to Tisha, one of the housekeepers, subsequently “cry and cry for hours.” In contrast, when former connections were absent, residents showed little, and often no, response.

Residents’ cognitive and physical status, as well as patterns of behavior, also affected responses. Residents with dementia tended not to develop close relationships or, as noted above, even to be aware of deaths or were confused about death information. Residents who mainly stayed in their rooms sometimes were not aware of the deaths of residents who sat at other tables or who themselves had been reclusive.

Residents’ tenure at the home and gender also influenced responses to death. After George Collins died, two residents reported to researchers that they would miss George in ways that related to his male status. Georgiana Stone liked that George used to call her his “sweetheart.” Savannah Smith said she missed talking to him about golf, as well as the fun she had his teasing him about “going on a date.” The long tenure of these three residents also influenced the degree of loss experienced by Savannah and Georgiana after George’s passing. George’s death also had an effect on the facility’s overall social environment because George was one of the few males who lived in the Dogwood building.

Sometimes a resident’s health condition affected response to her or his death. For some residents, George Collins was remembered as the man who typically sat in front of his door with a red Solo cup under his chin or who coughed loudly in the dining room. A researcher recorded the following after George’s death:

When I was sitting with Rebecca Thomas and Faith Deakins, Faith commented on how quiet it was in the dining room and noted that it used to be noisier. I had noticed myself that it seemed particularly quiet. I looked around and no one was having a conversation. Faith asked if I remembered the man who used to cough a lot during lunch, who has since

died. She was speaking of George Collins but did not seem to know his name. It almost seemed as if she missed the noise, any noise. She then went on to say that several people had died recently and that she had found it depressing.

In some cases, residents expressed relief in response to fellow residents' deaths. This relief was based on the suffering the deceased resident had experienced. When Felicity Matthews died, one of her tablemates, Rhonda Sutton, told a researcher that though she was sad that Felicity had died, she thought Felicity was better off because she was finally "at peace." Rhonda's response most likely was based on her religious beliefs. Rhonda, who was a Catholic, believed that death was a release from suffering because the deceased would find a better life in heaven. Religious beliefs also influenced Patty Felton's response to Madeline Smith's death. Patty commented to a researcher that Madeline was now probably in "a better place." Patty, like Rhonda, was a devout Christian.

Residents also were observed expressing condolences or sharing their own personal experiences of loss with the bereaved. The following passage from field notes on April 24th, 2009 shows condolences offered to Gina Bates after the death of her husband, Jim:

When Lily left her table, she stopped by Gina Bates' table and hugged and kissed her, expressing her condolences I assume. I heard Gina say she had never been kissed so many times as today. It was a very sweet exchange.

More than two months after Walter Hames' death, Rachel Houston, a resident who also lived in the Azalea building, told a researcher that she understood how "horrible" it was for Rita to be a widow" and how she had had a difficult time herself when her husband died at age 59. Rachel said that she had talked with Rita Hames and tried to offer her support.

Also in some cases, a resident's death generated no emotional response from fellow residents. For example, after Elizabeth Cummings died, no reaction to her death was observed among other residents. The absence of response likely related to Elizabeth's lack of connection to other residents, except for her husband, Henry. Elizabeth spent the majority of time in her room and for almost three months before she died she was in the nursing home next door. There also was no response after the deaths of Erving and Willis Tines. Similar to Elizabeth, neither had any close relationships with other residents and both had a short tenure at the home. The absence of emotional response among residents to the death of a fellow resident likely also stemmed from the regular occurrence of death in this environment, which may have served to normalize death. An example is Linda Bates' matter-of-fact reporting of the removal of Barbara Williams' body. Almost a month after Barbara Williams died, a researcher recorded on June 1st, 2009 in field notes:

Mrs. Mullins was sitting alone at her table. I asked her where Mrs. Grimes was and Mrs. Manning pointed to Barbara Williams' old spot and said totally nonchalantly, "Well, she died. And I don't know where she (meaning Mrs. Grimes) is – but she was here at lunch." This statement by Mrs. Mullins conveyed to the researcher that residents become accustomed to death.

In a few cases, more instrumental responses to a death occurred. One resident, Henry Cummings, moved completely out of the facility after his wife's death. Henry's move was facilitated by his own functional status and the fact that his son was willing to take him into his home. Jacob Irwin, however, chose to remain in his one-bedroom apartment in the Dogwood building. In contrast, Edith Burchfield's sister, Marie, moved to a smaller apartment when Edith died in order to conserve her financial resources.

Staff responses to resident deaths included feelings of sadness and loss and concern for the other residents who were still living. Staff responses were mainly influenced by the type of relationships they had with the residents, their tenure in the facility and in the LTC field, and the regularity of residents' death in the LTC environment. In general, staff members who were especially close to residents expressed more grief when these residents died than they did with other residents. For example, after Kevin Horton died, Tammi Bevin, a caregiver, told a researcher she was "very sad" because she had gotten "very close" to Kevin. Tenure tended to promote closeness, along with other factors that affected the development and maintenance of resident-staff relationships; both Kevin and Tammi had long a tenure at the Purple Home (four and seven years). During the announcement of Barbara William's death at lunch, a researcher observed Krystal, a care giver, facing the back wall of the dining room crying. Krystal had told a researcher that it was "impossible not to get close to them [the residents]" and when Elizabeth Cummings died, Krystal expressed her disappointment over being unable to go to her funeral. Roxy, a caregiver and former sitter for Natalie Billings, attended Natalie's memorial service and was moved by the video that showed pictures of Natalie's life.

Care staff also reported that they got used to death because of its frequency in the AL environment. When asked how she dealt with death, Krystal said, "I just learn to get used to it." After Beatrice Irwin died, Sandra, the activities director told a researcher that she had called her daughter and told her, "Another one has died."

Long-term care work experience also influenced staff responses to residents' deaths. Staff tended to worry about the effect of the death of one resident on another, especially when residents had particularly close relationships or were family members. Jessica and Mary Anne, two long-term staff in the Dogwood building, expressed the attitude that the death of one resident

would lead to the death of another. After Beatrice Irwin died, Jessica and Mary Anne told a researcher they thought that Jacob might not live much longer because of their long marriage and loving relationship. Mary Anne also worried about the effect of Felicity Matthews' death on her friends, Rebecca Thomas and Faith Deakins. Likely this attitude of both Jessica and Mary Anne was fostered by their lengthy work history in LTC and their experience with such occurrences. For example, during our study period, Willis Tines, one of the residents Jessica and Mary Anne cared for, died less than two months after the death of her husband Erving.

Formal Rituals

Formal rituals, including visitations, funerals, and memorial services, occurred in response to all deaths. Only in one case did a formal ritual take place at the Purple Home, a memorial service for Natalie Billings, a longtime resident who died at the nursing home adjacent to the facility. Natalie's sister, Esther, who had been a temporary resident at the Purple Home, other family members, and Natalie's former tablemates organized and conducted the service. The facility had no role other than to provide the space. A researcher attended the service and described the service in field notes from February 23rd, 2009:

I went over to Azalea about 3:15 to check on the memorial service and it was in process in the dining room. Natalie's family was sitting in chairs at the end of the dining room near the nurse's station. A table was set up with a punch bowl and cookies. Guests were sitting around the room. Natalie's tablemates were on the front row. Linda Bates got up to speak just as I entered. She told a story about Natalie and her relationship with her. Then Patty got up and did the same. Patty added that Natalie's son [who was a frequent presence in the home during Natalie's illness] was welcome any time to come visit. Esther Gentry then spoke about how important Natalie's tablemates were to her. She said the

first time she had visited Natalie at the Purple Home, no conversation was going on during meals. Once the present residents [those attending the service] moved to her table, conversation improved dramatically. She looked at Patty, Linda, Ruth, and Joshua [residents] while she spoke.

A number of other residents from the Azalea building, as well as three from the independent building, also attended the service. Natalie's son and daughter, several grandchildren, and other extended family were also present. Facility staff were notably absent. After the service, refreshments were served and then Esther invited everyone into the TV room to view a video that Natalie's twin brother had made of her life. Roxy Ellingsworth, a caregiver who also worked in the nursing home next door and cared for Natalie there, came into the TV room and sat by Esther. Roxy was visibly moved by the video and expressed grief over Natalie's death. In contrast, one of the activity staff stopped to watch the video momentarily and asked the researcher who Natalie was; the activity director showed a complete lack of interest in attending the gathering.

A combination of factors led to the formal remembrance of Natalie at the facility, including Natalie's tenure at the Purple Home, her sister, Esther's own short-term residence, and her close relationships with other residents. Natalie had lived at the Purple Home for over four years, and her long tenure helped her establish close friendships with her tablemates. As Esther mentioned during the memorial service, Natalie's tablemates meant a great deal to her and Esther wanted to give Natalie's friends a chance to remember and honor her. Natalie's tablemates had also embraced Natalie's handicapped son by letting him eat lunch with them and including him in activities such as card games.

Other formal rituals included visitations and funerals that were held outside of the facility. We were only aware of one resident, Mandy Cables, who attended a funeral of a fellow resident (Jim Bates). Except for the impromptu announcement and singing solo in the dining room after Barbara Williams died, there was no formal recognition of a resident's death by the facility. When asked by a researcher if the facility had services for residents after they died, Tina Matthews, executive director, replied: "We don't as a facility...we try to have a bus or van available to any of the residents that would like to go to the memorial services that are held here locally." Our data do not indicate that anyone took advantage of this service, or if in fact it was available, during the study period.

The Influence of Attitudes and Beliefs about Death and Dying

Our data reveal that various attitudes and beliefs were held by residents and staff regarding death and dying and these influenced these processes in AL. For the most part, the attitudes expressed were anchored in religious beliefs and in the experience of being old (for residents) and of living or working in the midst of residents suffering from chronic disease.

A consistent viewpoint articulated by residents was that death represents a release from suffering. Esther Gentry commented to a researcher that her sister's death was a "blessing" because she had suffered greatly while living. A researcher observed this interaction between two residents the day Barbara Williams died on May 8th, 2009:

The residents started filtering in for lunch and I was curious to see how quickly the news spread about Barbara's death. I moved over to talk to Madison Grimes. She didn't mention anything right off the bat, but shortly after I sat down, Linda [a fellow resident] walked by and said, "I'm so sorry about your friend." Mrs. Grimes said, "It's okay – I'm happy for her. She wanted to go!"

Being Barbara's friend and tablemate, Madison was keenly aware that Barbara had suffered considerably because of renal failure and she was happy that Barbara was finally at peace.

Another belief often expressed by residents was that death was a natural and normal event, especially in older age. Savannah Smith told a researcher that she believed that "conception is easy" and that the "end of life will be also" because like being born, dying is also a natural event. As discussed earlier, when Rebecca Thomas was put on hospice with four months left to live, she told a researcher, "I guess that's what happens when you live to be 92." Rebecca accepted that death was a natural and expected occurrence in old. A similar viewpoint was expressed by Patty Felton when she was asked in an interview how she dealt with the loss of other residents:

Well, I feel like that death is a natural thing. It's just the same as being born, and dying is just natural and normal. It's sad and it hurts ya to see your friends suffer, but when they pass, when you get to be as old as I am and most of the people around here, you know that they've gone to a better place, so you just reason it out. It doesn't make you less sad that they're gone, but you know that you certainly didn't want them to stay here and suffer.

Patty's words show additionally that she considers death a welcome relief from suffering, a belief that helped to mitigate the loss of friends. Patty also expressed a commonly heard theme of residents: that the deceased is in a "better place," a viewpoint influenced by a belief in an afterlife. Religion influenced other attitudes and beliefs about death and dying. Several residents stated that God, not humans, was in control of the timing of death. When Rebecca Thomas communicated to Faith Deakins that she had only four months left to live, Faith told Rebecca that doctors cannot make this prediction. Rather, "only God knows" when it is time for someone

to die. Faith's belief in God's sovereignty guided her conviction about the timing of one's death. Barbara Williams commented to a researcher after she had been on hospice for some time that she did not know why she was still alive. Answering her own question, Barbara simply concluded that "the Lord was not ready for me yet."

Religion also influenced residents' own readiness to die. According to a passage in field notes dated April 13th, 2009 (three weeks before Barbara's death), Barbara Williams' nephew reported that he thought Barbara was ready to die so that she could "see her husband, child, siblings and parents on the other side." In addition to her strong Christian faith, Barbara's suffering also likely influenced her apparent readiness for death. After Felicity Matthews' death, her tablemates told a researcher that Felicity had been "ready to go home" and that she had been "suffering for about two years." Similar to Barbara Williams, Felicity's death attitudes were influenced by her own suffering and her religious beliefs in peace after death. Some residents stated that they were "not afraid to die." A belief in an afterlife likely influenced this lack of fear of death.

Various attitudes and beliefs about death and dying also were expressed by care staff. Similar to the residents, religion influenced the attitudes of some. As mentioned earlier, Madeline Smith (see profile) started yelling out and moaning a couple weeks before she died. Madeline's outbursts were often a topic of conversation among staff as shown in the following passage from field notes on January 24th, 2009:

I sat in the back corner, near Madeline Smith's room. I [the researcher] suddenly heard her screaming for help, hollering and moaning, "Help! Help! My legs!!" I walked in to see if she was okay. She looked so incredibly frail. She opened her eyes briefly when I asked if she needed anything. She again said something about her legs and then she

appeared to go back to sleep. Kristina was walking by just as I was leaving Mrs. Smith's room. I told her what had happened and we walked back in together and Kristina said that Mrs. Smith was okay and she thinks that Mrs. Smith is "seeking salvation," which is something many people who are dying do. She said that those who have "been saved" die peacefully, but those who have not often yell and scream during the dying process.

Some attitudes expressed by staff tended more toward superstition. Cammie, another caregiver, stated that Madeline's "horrible, fitful death" made her wonder whether Madeline was "harboring a deep, dark secret." Cammie also said that it "freaked her out" that Madeline had died right after her son-in-law (who Madeline was not fond of) left the facility, indicating that she believed this phenomenon to be some sort of omen.

Summary of Findings

Overall, my findings show that residents experienced a variety of dying trajectories. Trajectories varied in duration and slope, with duration ranging from one day to seven months and slopes of decline that were gradual and as well as more steep and rapid. The main factors that influenced duration and slope were residents' health conditions and events and the point at which a resident was socially defined as dying. Physicians were significant players in the social construction of dying and typically, enrollment in hospice coincided with a physician's designation of the dying status. Hospice was an important element in the death and dying experiences of the majority of residents in my sample. Positive outcomes of hospice use included residents' ability to die at the facility, pain control, supplementary ADL care, and the provision of supportive medical equipment if needed.

For the majority of resident deaths, there was no formal way of communicating the death event within the facility. The primary way death was communicated was through "word of

mouth” among staff, residents, and residents’ family members. The responses to deaths depended on the nature of the relationship the deceased had with others. Significant grief was only observed when residents were also family members of the deceased, especially spouses. In non-family cases, resident responses to death were influenced by former relationships with fellow residents such as friends, tablemates, and/or neighbors. Staff responses to resident deaths included feelings of loss and sadness as well as concern for the residents who were still living. Except for one memorial service that was organized by a residents’ family, there was a lack of formal ritual that occurred at the home. Residents viewed death as a release from suffering and a normal and natural event, especially in old age. Religion played a significant role in many of the residents’ death attitudes and beliefs and many residents believed God was in control of the timing of one’s death. Religion also influenced attitudes and beliefs of staff regarding death and dying, but superstition also played a role.

CHAPTER 4

DISCUSSION AND IMPLICATIONS

My thesis has examined the experience of death and dying in AL. My research aims were to understand the processes of death and dying in AL and to understand how individual-, facility-, and community-level factors influence death and dying in AL. Therefore, my analysis focused on the residents who died during the study period. The findings I presented, though, encompassed others in these residents' social worlds and explored the multilevel factors that influence how all participants experience decline and death.

I used Glaser and Strauss' (1968) concept of *dying trajectories* to frame my examination of the experiences of residents who died during the study period. *Dying trajectory* here refers to the period beginning when a resident is defined by her or himself and others as dying and ending with death. Dying trajectories, or dying courses, have both duration and slope: duration denotes the time period of dying; shape refers to the slope of residents' decline as they approach death. My findings show that residents' dying trajectories varied in both duration and shape. Duration ranged from one to seven months; with respect to shape, trajectories included those where the slope of decline toward death was gradual as well as those where decline was more rapid. Some dying trajectories represented a continuation of the decline residents experienced prior to assuming the dying status.

Characterizing a dying trajectory, however, depends on establishing a point at which dying begins. My findings are consistent with Bern-Klug's 2009 findings with nursing home residents regarding the difficulty in some cases of determining the point at which a resident is in fact dying. Designation of the dying status is particularly challenging in LTC environments, including AL. Although the common pattern among the residents I studied was a dying trajectory

of gradual and steady decline, one resident improved enough to relinquish the dying status. In two other cases, residents with seemingly stable conditions, died suddenly.

My findings reveal that a principal factor influencing the duration and slope of residents' dying trajectories was their unique health conditions and events. Residents with long-term chronic health conditions, such as COPD, diabetes, and congestive heart failure, in general experienced trajectories with longer duration and gradual slope. These findings have implications for characterizing the dying experiences of residents of ALFs throughout the US, where such conditions are common. A survey conducted by the Assisted Living Federation of America (ALFA), shows that almost every resident in AL has one or more chronic conditions (ALFA, 2006).

Another significant factor that influenced the duration and slope of residents' dying trajectories was the point at which the resident was socially defined as dying. As Marshall (1975) put forth, and my findings support, dying is a social event and the dying status is defined by the individual dying as well as by others. The theory of symbolic interactionism (Blumer, 1969) provides a useful lens to view how residents and others define and negotiate the status of dying. Symbolic interaction emphasizes that social meaning is created through interactions with others. Through interpreting and evaluating the meaning of interactions, people define each situation and use these definitions to guide behavior. People thus "construct" the reality (Blumer, 1969, 5) of their social worlds.

Although residents' unique health conditions influenced their social constructions of dying, my findings show that residents with similar conditions varied in how and when the dying status was designated. Some were defined as dying months before death; others only days before they died. Marshall (1975) found variations in the social construction of the dying status across

the two LTC settings he studied. In his research in a nursing home, he found that residents were defined as dying only in the very last stages of life when they became seriously ill or required intensive care. In contrast, in a retirement home, Marshall (1975) found that the dying status was recognized much earlier in a resident's decline process. Death in this setting was a part of everyday life and something the residents actively planned for and accepted.

In her qualitative study of end of life care in nursing homes, Bern-Klug (2009) identified five categories of social interactions with respect to residents' dying status and care plan goals: *dying allowed*, *dying contested*, *mixed message dying*, *not dying*, and *not enough information*. As these labels suggest, the residents Bern-Klug assigned to each of the categories varied in the degree of consensus regarding care decisions, as well as in their conditions. Several of these categories are applicable to the residents in my sample. Most of the residents receiving hospice services fit the *dying allowed* category because the dying status was openly accepted (by the resident, family, facility staff, and physicians). Therefore, keeping the resident comfortable was the main goal. One resident on hospice was in the *dying contested* category. In this case social interactions conveyed open disagreement about goals of care. Though this particular resident was admitted to an inpatient hospice facility, his son did not accept his dying status and openly disagreed with the physician's care plan. Though I did not observe all five categories of Bern-Klug's categories, all types of interactions could easily take place in ALFs, which are increasingly common settings for resident death.

My findings also show that physicians were key players in the social construction of dying. Typically, enrollment in hospice coincided with a physician's designation of the dying status, which created certain visible signs in the home, such as the presence of hospice aides and

assistive equipment, which further influenced social definitions. The time at which physicians assumed this role varied.

Whether or not defined as dying, the majority of residents who died during the study period experienced a period of physical, and sometimes mental, decline prior to their deaths. This period of decline typically was accompanied by increased needs for care (both health care and personal care), withdrawal from facility social life, and often pain. Some residents were confined to their rooms or transferred to other LTC facilities during the final stages. All of these changes influenced their social interactions with fellow residents, family members, and facility staff, and thus the social constructions regarding the dying status.

Hospice was an important component in the death and dying experiences of the majority of the residents in my sample. Eleven residents used hospice services during the study, with utilization ranging from one day to seven months. The use of hospice provided extra attention and care and allowed eight of the residents in my sample to remain in the facility until they died. Other research shows that hospice services play a positive role in end-of-life care in nursing homes and ALFs by providing additional care, being a source of training and providing bereavement services to staff and families, and successfully managing residents' pain (Munn et al., 2008). My findings revealed a number of positive outcomes of hospice use for dying residents. The key benefits included the opportunity to die "at home," pain control, supplementary ADL care, and supportive medical equipment, which is consistent with hospice use in other LTC settings (Munn et al., 2008). Welch and colleagues (2008) reported that nursing home staff, who believe that hospice care complements the care they provide, also value the additional attention and emotional support hospice provide to dying residents.

In a national survey of hospice agencies, agencies were characterized by four types of services considered important to caregivers: medications and treatments; rehabilitative care; emotional, social, and spiritual support; and practical support (such as continuous home care) (Smith, Seplaki, Biagtan, DuPreez, & Cleary, 2008). This study found that slightly more than half of the agencies reflected a mix of the four types of services and the agencies that lacked multiple services could be distinguished by their lack of formal certification that officially recognized them as either a certified hospice or home health agency (Smith et al., 2008). The hospice agency used by residents in my study was certified and thus able to provide more comprehensive care.

Facilities also benefited from a resident's lengthened stay and the supplemental care from hospice aides. Allowing residents to die in place, however, was not without cost to the facility, primarily because of the increased care burden to facility staff. This downside of residents aging in place was not reported in the studies mentioned above (Munn et al., 2008; Welch et al., 2008).

A number of factors influenced the benefits residents received from hospice. One factor was the nature of a residents' illness. Residents with long-term chronic health conditions were the main beneficiaries of hospice. Resident and family awareness and sanction of hospice also affected hospice use and benefit. A lack of knowledge about hospice often delayed its use, which led to negative consequences for the resident, such as a delay in pain control. Welch and colleagues (2008), in their study of factors that influence hospice referrals, found that short lengths of stay in hospice do not allow for the physical symptoms to be effectively controlled. In an earlier study, Wetle, Shield, Teno, Miller, and Welch (2005) found that hospice enrollment for residents was delayed because nursing home physicians were "missing in action." Other

research cites late referrals by physicians (Smith et al., 2008) as contributing to low utilization of hospice.

In my study, facility sanction was necessary for hospice use. Cartwright and colleagues (2008), in their study of end of life care in AL, also found administrator support to be a key factor in hospice use and in residents' ability to die in the ALF setting, both of which promoted good end-of-life care. This study further found that respectful collaboration among multiple care providers, such as facility and hospice staff and family members (when present), is associated with good care for the dying residents (Cartwright, et al., 2008). My data did not include information about collaboration between care workers, but it is likely that some collaboration was present and that it exerted similar influence.

A main tenet of AL philosophy is for the resident to be able to age (i.e., die) in place in an ALF (Hyde, Perez, & Reed, 2008). However, more and more ALFs are admitting and retaining residents with greater physical and cognitive impairment (Golant, 2008), which results in increasing frailty in the overall AL population. Therefore, it is becoming more difficult for some residents to age in place in the AL setting, and ALFs either have to discharge residents or lower their eligibility requirements. Ball and colleagues (2004) found that the ability of residents to remain in ALFs was mainly a function of the "fit" between the capacity of both residents and facilities to manage decline. A key facility factor affecting aging in place was the degree to which a facility adjusted staffing levels to accommodate declining residents' increased care needs. The findings from my study indicate that hospice helped the Purple Home manage decline and allowed more residents to age in place; no adjustments to staffing levels were made.

Physical and cognitive impairments are not the only factors that affect residents' ability to stay in an ALF; their financial resources are also a significant factor since most ALFs are

private pay (Ball et al., 2004; Hawes, Rose, & Phillips, 1999). I also found financial resources to influence aging in place for some of the residents at the Purple Home. During the study period, one resident had to move to more affordable facility out of state and another resident had to move to a smaller, less expensive room in order to remain at the home. Others voiced a fear of running out of money before they died.

Six of the residents in my study died in their rooms in the facility. Although some residents were matter of fact or nonchalant about witnessing, for example, the removal of a body, such occurrences undoubtedly had impact on the social environment. My findings show that facility staff attempted to shield residents from witnessing the removal of bodies. Munn and colleagues (2008) found that some ALFs ensure that residents do not witness the removal of bodies by closing doors and removing all residents from common areas and hallways, while other facilities consider hiding the removal of bodies unnecessary and simply remove them through the main lobby or entrance.

For the majority of resident deaths, there was no formal method for communicating the death event within the home. The primary way death was communicated was through “word of mouth” among staff, residents, and residents’ family members. When residents were neighbors, tablemates, or friends, news traveled more quickly. Gubrium (1975) found similar types of death event communication in the nursing home he studied. Our findings show that staff rarely communicated death information to residents. This practice is consistent with Shield’s (1988) findings where she observed that staff also avoided telling residents about fellow residents’ deaths because they wanted to protect the residents from the sadness and unpleasantness of death. A significant barrier to staff communication of information about death and dying in the Purple Home was HIPPA. Data showed no instance where information about deaths was posted

in a public location, which was consistent with Shield's (1988) findings where she also observed no public notices of resident deaths in the nursing home setting. My findings revealed, however, subtle clues of death in the facility environment, including funeral floral arrangements and plants, tokens of appreciation from families, increased presence of family members, the absence of a resident at meals or activities, and the refurbishment of the deceased resident's room. Shield (1988) also reported environmental indicators, such as the bed and room being cleaned after a death so that a new resident could be admitted.

Responses to resident deaths depended on the nature of the relationship the deceased resident had with others, including fellow residents, family members, and facility staff. Significant grief was only observed in cases of residents who were also family members of the deceased, especially remaining spouses. My findings were consistent with research that has shown that older spouses rely more on one another for support than on external social relationships (Barrett & Lynch, 1999; Johnson, 1985; Kemp, 2008), especially if one spouse is more dependent on the other. Several of the couples in my sample consisted of a spouse who was more impaired, and therefore more dependent, on the other spouse. The dependence of one spouse on the other was especially difficult if the more independent spouse died. Gladstone (1995); Kemp (2008); Moss & Moss (2007); and the National Advisory Council on Aging (1993) found that spouses in ALFs appreciated having one another as companions, advocates, helpers, and sources of emotional support and continuity. Because the spouses in my sample were close companions, the death of a husband or wife produced responses such as grief, depression, or loneliness. In the case where the more independent spouse died, the more dependent spouse was left without her husband's daily support.

In non-family cases, resident responses to death were influenced by former relationships with fellow residents, such as friendship or being neighbors or tablemates. Residents who had been friends usually conveyed a sense of loss or sadness, which is consistent with Gubrium's (1975) finding that friendship among nursing home residents makes death an interpersonal ending in addition to a public one at the home. In some cases, residents expressed relief in response to fellow a resident's death because of the suffering the deceased resident had experienced. In some cases, however, a resident's death generated no response from other residents. Absence of response was mainly due to a lack of prior relationships between the deceased and fellow residents and to the regular occurrence of death in the facility, which served to normalize death in the environment. This finding regarding the normalization of death is consistent with Gubrium's (1975:204) research, where he found a lack of response to resident death because, according to others at the nursing home, death was a very reasonable event to expect "in a place like this."

Staff responses to resident deaths also included feelings of sadness and loss, as well as a concern for the residents who were still living. A significant factor that influenced the responses of staff was the type of relationship they had with residents. In general, staff who were especially close to residents expressed greater grief when these residents died, which is consistent with other research addressing staff-resident relationships in LTC (Ball, Lepore, Perkins, Hollingsworth, & Sweatman, 2009; Moss, Moss, Rubenstein, & Black, 2003; Savishinsky, 1991). Savishinsky (1991) reported in his nursing home ethnography the devastation of staff over the death of a resident who had lived at the nursing home for 17 years. My findings also demonstrated the effect of resident and staff tenure on staff responses to death. After a resident who lived at the Purple Home for four years died, a staff member with a seven-year tenure

expressed her sadness to researchers. Long tenure in the home greatly contributed to the closeness some staff and residents shared with one another.

Formal rituals, including visitations, funerals, and memorial services, also occurred after all the deaths in the Purple Home. However, only in one case (a memorial service organized by the deceased resident's family) did a formal ritual take place at the home. The lack of formal response to death by the facility was consistent with Shield's (1988) findings in the nursing home setting, where on one occasion, in protest, a resident organized a memorial service for a friend who had died. In a national study of nursing homes, Moss and colleagues (2002) found that less than half of the facilities in their sample reported that they had memorial services for deceased residents in the previous year. Shield (1988) notes the importance of acknowledging death in the nursing home setting because it can foster the development of group solidarity. Savishinsky (1991) suggests having established procedures for dealing with death that address the social and emotional impact on those left behind.

My findings revealed various attitudes held by residents and staff about death and dying. In large part, the attitudes expressed by residents were influenced the experiences of being old and suffering from chronic disease. A consistent viewpoint articulated by residents was that death was a release from suffering. Marshall (1975) found a similar attitude among residents in the nursing home setting he studied. Other research also found that residents in AL and nursing homes expressed a readiness for death because it would provide an escape from possibly a further decline in health status (Shippee, 2009).

Another belief often expressed by residents at the Purple Home was that death was a normal and natural event, especially in older age. My findings are consistent with research that has found a parallel pragmatic attitude among nursing home residents (Gubrium, 1975;

Savishinsky, 1991; Shield, 1988). The attitudes of these nursing home residents, like those of the residents in my sample, were fostered by their experience of being constant witnesses to death.

My findings also found that religion influenced AL residents' attitudes about death and dying. The attitude that God is in control, especially about the timing of one's death, is comparable to the attitude Marshall (1975) found among residents in a Catholic-run nursing home. A belief in an afterlife also contributed to residents' readiness to die and lack of fear regarding death. Patterson and colleagues (2003) found that religious faith helped AL residents to prepare for their own deaths and to maintain continuity in the face of change, such as the death of fellow residents. Other AL research (Eckert, Zimmerman, & Morgan, 2001) has found that commonality in religious beliefs sometimes bring residents closer together, which can possibly decrease the negative impact of a fellow resident's death.

Similar to residents, religion also influenced some of the attitudes of staff members regarding death and dying. However, other attitudes expressed tended more towards superstition. In contrast to my findings, Shield (1988) found that staff avoided any type of discussions about death and Savishinsky (1991:161) observed staff avoided death talk because to them, "death was a taboo subject."

Implications for Policy and Practice

Residents experience death and dying in AL in various ways, whether through experiencing the dying process themselves or by observing the dying and death processes of other residents in the home. My findings illuminate a number of issues that are central to the experience of death and dying in AL. Since resident deaths range from 14 percent to 22 percent annually in AL (Golant, 2004; Zimmerman et al., 2005), it is essential that these issues be

addressed in the wider AL setting. In the section below I will discuss these issues and suggest recommendations for policy and practice related to these issues.

Participation in hospice has a significant impact on how residents experience dying in AL and increases their ability to age in place. Taking into account the four types of services Smith and colleagues used to characterize hospice agencies and my own findings from research in the Purple Home, I believe the type of hospice agency that would be best for the AL setting would be one that offers various services that meet the unique needs of the residents, family, and facility staff. Thus an agency that provides the full range of hospice services, including medications and treatments and rehabilitative care to residents and emotional, social, and spiritual support to all three parties would be optimum in AL. Specifically, hospice should provide bereavement services not only to residents and their families, but also to care staff. A bereavement coordinator who is available to staff to offer support and counseling is important since staff sometimes form close bonds to the residents and experience grief when they die. An ideal hospice agency would also include facility staff in the plans of care for dying residents given the fact that facility caregivers have cared for the residents before they were given the dying status and thus have the best knowledge of them.

Death education regarding end-of-life issues including various illnesses, funeral/disposition issues and advance directives (Gross, 2004) also is needed for residents and their families, as well as facility staff since they assist hospice staff in caring for dying residents. Death education can be provided by hospice bereavement coordinators, local clergy or certified grief counselors. Death education has a great deal of benefits. According to Gross (2004), through death education, staff provide better care to the dying and also meet the needs of the bereaved (such as other residents) more effectively. Though death education may constitute an

extra cost to the facility, it is a good investment because, according to Gross (2004), staff will feel more comfortable caring for dying residents and the residents will feel more assured knowing that staff understand their needs and concerns. Death education also teaches residents and their families about the services hospice provides and the different options that are available with end-of-life care.

Formal mechanisms should be established for communicating and acknowledging resident deaths in ALFs and residents should have a role in deciding how these formal mechanisms are structured. A death could be communicated verbally in a public venue, in written material displayed in public areas, or in more symbolic ways such as the placing of a rose at the resident's dining place, hanging a purple bow on the resident's door, or having a prayer or moment of silence in memory of the resident during a meal. Other ways of acknowledging death could include memorial services where residents have a role in planning the details of the service, as well as leading it. A facility also could institute a support group for residents to allow them to share their grief and feelings of loss with others.

Because AL research has indicated that individuals at the corporate level or facility administrators set policies regarding how deaths of residents will be handled (Ball et al., 2005), it is imperative that these individuals also be properly educated by professionals such as hospice bereavement coordinators, clergy or grief counselors, on the importance of end-of-life issues such as advance planning, death anxiety, grief, and bereavement.

My findings indicate that being able to die in AL is important to residents and their families. For this outcome to be possible with minimal complications, though, facilities may need to implement new policies and procedures. Because hospice does not provide day to day care, facilities need to increase the staffing levels in order to accommodate the extra care burden

that is put on staff and prevent possible neglect of other residents. I acknowledge the extra cost of increasing staff and the possibility of facilities having to raise resident fees, but hiring additional staff will result in a higher quality of care, which will in turn increase resident retention.

Because the goal of aging in place in AL is increasingly beyond the financial means of many older adults with low or modest incomes, there is a need and current demand for more affordable AL options (Stone, Harahan, & Sanders, 2008). Some means of increasing public funding for AL may be the only solution to this problem, a solution that faces considerable obstacles given the current economic situation.

Lastly, it would also be beneficial for residents to make plans for their own deaths before moving into AL. By having an advance health directive, residents' wishes for treatment during their dying process and/or after their death are clearly stated. It is also important for residents to express their death and dying wishes to family members who are actively involved in their lives. If family members know a resident's wishes, they can ensure that the resident's wishes are honored. In addition, I think it is beneficial for all ALFs to require residents to have completed and current advance directives. In Marshall's (1975) research in a retirement home community, administration required residents to have wills, designated executors, and specific plans for the disposition of their bodies (which an advance directive now covers).

Limitations and Suggestions for Future Research

A primary limitation of this study is that it is a secondary analysis of data from a study that focused on relationships among residents in the AL setting, not specifically on death and dying. Therefore, formal and informal interviews and participant observation addressed resident relationships and the factors that influenced them in a more general way without specific

attention to death and dying. Though death influenced resident relationships and death and dying events were observed by researchers during visits, I am still lacking detailed information about specific aspects of the death and dying processes in the home. In addition, because my data came from only one ALF in Georgia, the generalizability of my findings is limited.

Future qualitative studies should use a larger sample of facilities and residents and focus data collection on death and dying. It also should include interviews with family members and hospice administrators and caregivers. Future studies should also try to ensure that researchers are present for as many deaths and rituals (such as memorial services) as possible in order to fully understand how death and dying is handled.

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