GRIEF IN LONG-TERM CARE: A STUDY OF THE IMPACT OF DEATH AND THE BENEFITS OF END OF LIFE PLANNING ON LONG-TERM CARE STAFF

By

AMANDA ALEXANDRA BROWN-BRUNDAGE

(Under the Direction of Toni P. Miles)

ABSTRACT

Statement of the Problem: Grief suffered by staff in long-term care (LTC) facilities is a public health issue. Multiple studies show that the death of a family member can have an impact upon mortality, morbidity, and healthcare expenditures among the bereaved. In the long-term care setting, qualitative and quantitative studies show that (1) staff and residents develop a familial relationship, and (2) staff suffer a variety of grief symptoms when residents die. There is a need to address the bereavement needs of the LTC workforce, particularly in light of shortages in the healthcare workforce. These shortages are particularly severe among nurses and certified nursing assistants (CNAs) within the LTC setting.

Purpose of the Study: To document the grief experiences of LTC staff and benefits of end of life planning.

Methods: The first manuscript provides a systematic review of the literature on long-term care staff grief using the PRISMA methodology. It includes quantitative, qualitative, and mixed methods studies. The second manuscript contains a qualitative content analysis (QCA) of seventeen interviews with 28 LTC staff and hospice chaplains that work with them. Those interviews were analyzed for grief symptoms, cumulative loss, and added stressors within the LTC setting. The final manuscript adopts a novel mixed methods approach through the use of QCA and legal analysis. The QCA analyzes the same seventeen interviews for discussions of end of life planning. The legal analysis involves cases brought by family members of deceased for the pain and suffering that they suffered as a result of the hospital's failure to follow the end of life wishes of their loved ones, and it includes detailed descriptions of the legally compensable pain that they suffered.

Results: LTC staff suffer extensive grief symptoms due to the death of their residents. This pain is often exacerbated by cumulative losses, stressful interactions with family members, and failures in end of life planning. The Physician Orders for Life-Sustaining Treatment (POLST) is an effective tool to promote end of life planning.

Conclusion: LTC facilities should develop provide bereavement resources for staff and promote end of life planning through use of the POLST.

INDEX WORDS: Bereavement, Long-term care staff, End of life planning, Grief, Loss, Death, Systematic review, Qualitative content analysis, POLST, Caregiver

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A Dissertation Submitted to the Graduate Faculty of The University of Georgia in Partial Fulfillment of the Requirements for the Degree

DOCTOR OF PUBLIC HEALTH

ATHENS, GEORGIA
2020

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DEDICATION

This dissertation is dedicated to my daughter Robyn and my husband Sean. Without their love and support, I would never had completed it.

ACKNOWLEDGMENTS

I would like to thank the chair of my dissertation committee, Dr. Toni P. Miles, for the extensive, guidance, support, and resources that she has provided me over the past five years. Without her help, I would not have arrived at this point. I would also like to thank the other members of my dissertation committee, Dr. Lesley Clack and Ms. Pam O'Rourke, for their guidance and support throughout the dissertation process. Both have taken the time to revise my manuscripts and provide numerous helpful comments. In addition, I would like to thank Ms. Courtney Skelly for her invaluable assistance during the coding process. Finally, I would like to thank Dr. Jerry Gale for his advice regarding qualitative research design.

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CHAPTER 1

INTRODUCTION

SHORTAGES IN THE HEALTHCARE WORKFORCE

For many years, the United States and other nations have suffered from severe shortages in the healthcare workforce. A recent study indicates that by the year 2030, there will be an estimated shortage of more than 500,000 nurses in the United States. This shortage will be concentrated particularly in the southern and western regions of the nation.[1] The new generation of older adults will be more racially/ethnically diverse, have greater longevity, be more highly educated, and have more dispersed families.[2] There is a need for more racial, ethnic, and gender diversity as well as greater levels of education/training within the long-term care (LTC) workforce.[2,3]

In the LTC setting, shortages in nurses and nursing assistants have been recognized since the 1990s. As early as 1996, researchers noted that nursing shortages in the long-term care setting are even more serious than other settings.[4] Several years later, William Scanlon, Director of Health Care Issues, delivered a speech to the United States Senate about shortages citing his concerns about recruiting and retaining both nurses and nurse aides. He noted the rapidly growing numbers of individuals over 65 and of individuals over 85 and the consequent need to increase the size of the workforce.[5]

Turnover also plays a role in these shortages. One 2019 survey of 152 registered nurses working in a hospital, large health system, or long-term care facility found that 91% of human resources executives working in healthcare believe that retention is more important than recruitment. Only 57% of nurses surveyed believe that "their organization is doing all that it can to retain good nurses." In addition to a high salary, most nurses value paid time off (91%) and flexibility in their schedules (87%).[6,7]

Addressing the Needs of Long-Term Care Workers

These statistics illustrate the importance of working to meet the needs of the healthcare workforce, particularly in long-term care. The number of Americans over the age of 65 has grown by 34.2% between 2010 and 2019,[8] and the population over the age of 85 has grown by 20.2% during that time period.[9] The care provided by long-term care staff is essential to this population; however, they cannot be effective caregivers if their own needs have not been met.

The public health impact of grief is well-established. The death of a family member leads to increased risks in mortality, morbidity, and healthcare utilization.[10-12] A small but growing body of work suggests that LTC workers also suffer substantially from losses of their residents. Often, they develop a familial relationship with the residents for whom they provide daily care. These residents inevitably die. In many cases, the grief that staff feel from the loss of residents is compounded by grief experienced by losses of family members or close friends. However, many long-term care workers have reported that they are not permitted to grieve.[13] Some have reported symptoms of burnout, and multiple authors have suggested that this can lead to turnover and diminished quality of care.[14-17]

Gaps in the Literature

A limited number of qualitative and quantitative studies document grief symptoms suffered by long-term care (LTC) staff due to resident deaths; however, there has never been a systematic review of the qualitative and quantitative studies addressing LTC staff grief. In addition, existing studies of LTC staff grief do not examine physical symptoms of grief or the impact of cumulative loss.

While several studies describe the benefits to LTC staff when residents suffer a “good” (calm, peaceful) death, they do not examine the impact of end of life planning on this process. They also do not consider the role of staff interactions with the deceased residents’ families. In some cases, family members may manifest their grief through anger. In other cases, staff empathize with their visible and sometimes physical manifestations of grief. Finally, those studies do not consider the interplay between grief and other stressors within the LTC setting, such as difficult residents and excessive bureaucracy, rules, or paperwork.

DESCRIPTION OF THE MANUSCRIPTS

This study includes three manuscripts. The first manuscript (Chapter 2) contains a systematic review of the literature on LTC staff grief using the PRISMA methodology. To address a problem, one must understand the problem, and to my knowledge, it is the only systematic review that analyzes qualitative and quantitative studies of grief suffered by long-term care staff. Due to the dearth of literature in the field, this review includes studies that date back to 2000. It includes twelve qualitative studies, five quantitative studies, and two mixed methods studies. It documents common symptoms of LTC staff grief and some of the factors that can exacerbate them. Most of the quantitative studies use validated instruments to assess grief and associated burnout, such as the Texas Revised Inventory on Grief and the Maslach Burnout Inventory.

The second manuscript (Chapter 3) contains an in-depth qualitative content analysis of seventeen interviews with LTC staff and the hospice chaplains that work with them. Some interviews include multiple interviewees, so the total number of interviewees is 28. These interviews were undertaken as part of two projects funded by the Centers for Medicare and Medicaid Services (CMS) to improve bereavement care and end of life planning in LTC facilities. Here, I thoroughly analyzed all sections of the interview transcripts that related to grief symptoms, discussions of cumulative loss, and added stressors. I selected the specific categories within each domain based upon my review of the literature and my personal knowledge of the subject matter from four years of fieldwork.

Chapter 3 fills in multiple gaps in the literature. In addition to providing confirmatory evidence of the grief symptoms described in my systematic review of the literature, I also examined the transcripts for several symptoms that are not found in the literature. Next, I searched for evidence of the aggravating effect that cumulative loss has on grief. Many professional caregivers have also worked as informal caregivers for loved ones, so I examined the grief causes by the combined loss of residents and family members or close personal friends. Finally, I considered a wide range of factors that can exacerbate LTC staff grief.

In the third manuscript (Chapter 4), I examine the impact that end of life planning, or the lack thereof, has on the grief experiences of LTC staff and family caregivers. To the best of my knowledge, this is a novel type of analysis that has never been previously performed. Generally, the case for end of life planning stems from arguments related to the rights of an individual to determine the form of treatment that he/she receives and the huge health savings associated with not performing often unwanted life-sustaining procedures. In a limited number of settings, individuals have discussed the extensive pain suffered by patients, already in a frail condition, undergoing aggressive life-sustaining treatments despite having no chance of recovery. However, to the best of my knowledge, nobody has analyzed the impact that these treatments have on the grief suffered by LTC staff and family caregivers.

I adopted a novel mixed methods approach to analysis by combining legal and qualitative methodologies. This differs from the traditional mixed methods study which utilizes quantitative and qualitative analysis. For the legal analysis, I consider successful lawsuits in which the plaintiffs have sued medical providers for providing unwanted and painful life-sustaining treatment. In these cases, the plaintiffs sued not only on behalf of the deceased family member, but also on their own behalf, for the trauma that they personally suffered from witnessing their loved ones undergo unwanted treatment.

Qualitatively, I evaluated the same set of interviews as I did in chapter three, but I focused on discussions of end of life planning and its impact on staff and residents. Staff describe the benefits of a calm, peaceful death and not having residents undergo painful and futile life-sustaining treatments. They also describe the added stress of not having a single, clear decisionmaker. Finally, the analysis looks at best practices related to end of life planning. Staff describe their experience using the Physician Orders for Life-Sustaining Treatment (POLST), a one-page physician's order, signed by a physician and a patient, that provides clear and concise information about the resident's end of life preferences. This is a legally recognized document, and in most states, medical providers who follow the instructions set forth on the POLST are immune from liability. Staff also discuss the importance of describing death as a natural process and focusing on alleviating pain and keeping the dying person comfortable during their last moments.

Each manuscript contributes to the understanding that we have of grief in the long-term care setting. The first manuscript systematically reviews the literature for discussions of grief.

The next manuscript includes a detailed analysis of seventeen interview transcripts for symptoms of LTC staff grief, cumulative loss, and added stressors. Finally, the last manuscript focuses the effect that end of life planning (or the lack thereof) can have on the grief of both family members and staff.

CHAPTER 2

THE ADVERSE IMPACT OF GRIEF ON LONG-TERM CARE: A PRISMA-BASED SYSTEMATIC REVIEW[1]

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[1] Brown-Brundage, A.A. & Miles, T.P. To be submitted to the *Journal of Pain and Symptom Management*.

ABSTRACT

Context: In the age of COVID-19, there is growing recognition of the impact that grief has on healthcare workers, particularly in the long-term care setting. There is a need for a systematic review of quantitative, qualitative, and mixed methods studies that document this grief.

Methods: This is a systematic review analyzing quantitative, qualitative, and mixed methods studies of emotional responses among post-acute care workers to resident deaths. This review applies the Prisma methodology. The topic is cross-disciplinary. To obtain the broadest evidence, we used a multi-database search tool to look for articles in 127 databases.

Results: We completed three searches. Nineteen articles met the inclusion criteria. Methods varied across reports – with five quantitative studies, twelve qualitative studies, and two combining both methods. Studies included 3,247 total participants. An experience of grief similar to that of family members was reported in 12 studies. Eight studies reported staff crying in response to death. Seven studies report emotional detachment among staff: a potentially problematic response that diminishes quality of care. Eight studies reported that grief is increased if staff do not have the resources to provide optimal care. Finally, six found that grief is increased if the process of dying is prolonged, painful or unexpected.

Conclusion: Caring is optimal when staff develop familial relationships with patients. This bonding leads to suffering when death occurs. The evidence clearly shows that staff well-being and quality of caregiving are at risk after patient death. These workers report feeling pressured to hide their grief and cope by emotionally detaching from patients. Emotional detachment is not a positive approach to mitigating grief. Successful mitigation occurs when bereavement care is available for workers. Maintaining these professional caregivers is paramount to society's ability to provide quality care to adults in the final stage of their life.

INTRODUCTION

Grief suffered by staff working in long-term care (LTC) facilities is a public health issue. In 2017, a total of 2,813,503 deaths were registered in the United States—69,255 more deaths than in 2016.[18] Multiple studies illustrate an increased risk in mortality among the bereaved in the familial setting.[10,19] Recent studies have also shown the impact that death can have on morbidity. The bereaved can experience physical symptoms such as insomnia and increased healthcare utilization.[11,12] To the best of our knowledge, no longitudinal studies have been completed to document the impact of loss outside the family setting; however, studies document the familial nature of relationships between staff and residents in long-term care (LTC) facilities.[20,21]

The objective of the literature review is to analyze the quantitative and qualitative studies on the existence and impact of grief from resident death on LTC staff. It is useful to contemplate the nature and extent of staff grief within LTC facilities before analyzing interventions meant to alleviate it. Do LTC staff suffer from grief, as a result of the death of residents, that could adversely impact well-being, "burnout" from work, job satisfaction, or likelihood to remain in current employment? This manuscript is a systematic review of the literature using the Prisma method. To the best of our knowledge, no such systematic literature review has previously been completed.

METHODS

Data Sources

To find cross-disciplinary studies, we used an advanced multi-database search tool. Table 1 lists the databases yielding initial results and the number of results from each.

Search Strategy

The search identified articles with the following words in the abstract: “long term care” OR “long-term care” OR “nursing home” AND grief OR bereavement AND staff OR “nursing aide” OR “nurse aide” OR “certified nursing assistant” OR “CNA.” The first three terms designated the setting: long-term care (LTC). The second two terms designated the subject of interest: grief or bereavement. The remaining terms designated the focus of staff experiences. We conducted a bibliographic analysis of articles published in 2010 or later, and we conducted an additional search for articles which had the terms “nursing home,” “staff,” and “dying” or “death” in the abstract. This search was limited to articles published between 2014 and 2019 and written in English.

Selection of Studies

Included studies directly address the impact of grief from resident death on LTC staff. Two studies also included home health aides, who care for a similar population. We excluded studies that were (1) not published in a peer-reviewed journal; (2) written in a language other than English; (3) written by an author without a Master’s degree or Doctoral degree from an accredited institution; (4) took place outside of North America, Europe, or Australia; or (5) were published before 2000. In addition, to eliminate bias, no more than two studies with the same datasets were included.

RESULTS

The PRISMA Flow Diagram (Figure 1) shows that the database generated by the initial criteria yielded 79 results. A bibliographic search of the articles published in 2010 or later produced sixteen additional articles (total: 95). We excluded 58 articles that were clearly outside of the scope, not data-driven studies, or published before 2000.

We eliminated 21 of the remaining 37 studies for other reasons: two were due to serious methodological issues (n=2) and the others were outside of the scope. This includes two intervention studies (n=2); three studies that looked at the grief of other medical professionals (n=3); three studies based upon the same datasets as other included studies (n=3); and eleven studies that failed to document staff grief or its effects (n=11). Sixteen studies fit the search criteria: five quantitative studies, nine qualitative studies, and two mixed methods studies. One mixed methods study was a 2-part study with an initial qualitative study done to help formulate questions for a later quantitative study. The other included qualitative data from group sessions and quantitative survey data. After completing this initial review, we conducted an additional search for articles which had the terms "nursing home," "staff," and "dying" or "death" in the abstract. Six articles met these criteria, but three were eliminated based on the obscurity of the journal.

Detailed Description of Study Attributes

Table 2 describes the qualitative studies and the qualitative portion of the mixed methods studies in this review. For each study, it provides the topic; sample size and description; methods of analysis used; and source. [13,20-32] Table 3 describes the quantitative studies and the quantitative section of the mixed methods studies. For each study, it provides the topic; sample size; sample description; data; method(s) of data analysis; and source.[14-17,22,23,33]

Studies took varying approaches to selection of participants. Some invited all eligible, available individuals within their setting to participate. Each reported their participation rate. Eligibility criteria sometimes limits participants to those who have recently had a resident die[14,15] or those with a specified number of years of experience.[24,26] One study was limited to nursing assistants who had recently had a deceased resident that refused life-sustaining treatment, and relied upon a senior nurse to select eligible participants.[23] Some studies focused exclusively on nursing assistants,[14-17,23] while others included all LTC staff.[22,33] Two studies recruited available volunteers at randomly selected facilities (without inviting all eligible staff to participate).[16,17] One study ensured geographic diversity by using urban and rural facilities in Kansas, Pennsylvania, and New York,[33] but other studies were limited to a single region. Table 4 shows the specific grief symptoms reported by staff in each of the studies.

Overview of Results: Consensus and Unique Findings

1. Staff working in LTC develop a familial relationship with residents and suffer symptoms of grief as a result of resident death.[13,20,21,23-29,31,32]
2. Staff grief is exacerbated when resident deaths are unexpected, prolonged, painful, or when staff do not feel that they were able to provide sufficient care.[13,15,21-25,28-30,32]
3. Staff commonly report crying due to grief.[13,15,21-23,25,27,33]
4. Depersonalization (detachment or avoidance of contact with a dying resident) is a common grief coping mechanism for staff.[13,15-17,21,24,29]

Detailed Description of Study Findings

Impact of Grief on Depersonalization / Detachment

Three quantitative studies examined the association between grief among LTC staff and burnout[14,16,17] using the Maslach Burnout Inventory (MBI)).[34] The MBI includes three forms of burnout: depersonalization, emotional exhaustion, and diminished personal accomplishment.[34] All three studies found that grief symptoms are significantly associated with depersonalization,[14,16,17] which is “a key component of burnout…reflected in a sense of cynicism and detachment.”[14] Complicated grief, a DSM V diagnostic category, is also associated with depersonalization.[16] In addition, grief avoidance (refusing to think about or talk about the deceased) is associated with depersonalization.[14] Finally, there are strong positive associations between grief-related distress and depersonalization and between “no growth from grief” and depersonalization.[17] Growth from grief refers to positive coping and emotional growth and is measured through a validated survey.[17,35]

Four qualitative studies document the relationship between grief and detachment.[13,21,24,29] As noted above, detachment is a clear manifestation of depersonalization.[14] Staff report coping with grief by attempting to emotionally detach themselves from residents to enable them to continue with their difficult work.[29] Residential care aides (RCAs) sometimes manage “difficult emotions…by trying to detach themselves.”[29] One RCA explained that, after struggling with his emotions following the death of a resident, he began “pulling himself back” from his patients.[29] Another RCA explained that caring for dementia residents is much easier if you remain totally detached. A third explained that “either I have to shut my emotions off so I can deal with all these deaths, or I have to make a decision to love them anyway and grieve when they’re gone.” She continued by explaining that “I’ve always said that if [resident death] doesn’t affect me, I’m leaving. I’m burned out.”[29]

Staff “have dual responsibility to effectively attach to residents in an effort to provide what they describe as quality care, while they must be able to detach when the resident dies to carry on with their routines.”[13] One staff member described avoiding contact with dying residents altogether whenever possible.[24] Staff tend to “prevent feelings of grief from occurring through adopting an emotionally detached approach to their work and their interpersonal interactions with patients and families.”[21] This involves actively avoiding patients for whom they might grieve and avoiding the development of emotional attachments altogether.[21] One staff member explained “You have to go into it knowing to guard yourself too because you can’t become too emotionally attached either.”[21]

Grief and Well-Being

One quantitative study explicitly examined the relationship between grief and physical and psychological well-being. It used a validated scale (Perceived Well-Being Scale-Revised)[36] to measure both physical and psychological well-being of participants. Participants were asked eight Likert-scale questions related to physical well-being and eight related to psychological well-being.[17] Self-rated health is a commonly used metric in social science research, and a robust indicator across, language, cultural groups, and time. The authors ran linear stepwise regressions to determine the relationship between grief and well-being. Distress from grief was significantly associated with poor self-reported psychological well-being, and growth from grief was significantly associated with positive self-reported physical and psychological well-being.[17] This finding is supported by quantitative and qualitative studies which report higher levels of, sadness, crying, and pain following resident deaths. [13,20,21,23-29,31,32]

Personal Accomplishment and Job Satisfaction

Failure to feel personal accomplishment in one’s work is a validated measure of burnout and another subscale on the Maslach Burnout Inventory (MBI). There is quantitative[16] and qualitative[13,26,29,32] evidence suggesting that personal accomplishment is associated with job satisfaction. Attaining higher rates of job satisfaction is crucial to combat turnover within this community.

Feelings of Grief in LTC Staff

Quantitative studies of staff include 1868 participants from two nations and in 84 facilities. Most individuals reported grief or stress after resident death. There is a dose response relationship between number of resident deaths in the past month and number of grief symptoms (Spearman rho = 0.20, P = 0.007). In one study, 78% of staff members reported that death affects their emotions.[33] In another study, LTC staff interviewees overwhelmingly stated that "the confrontation with death is often stressful."[22] In particular, both nursing staff and non-nursing staff widely found that it was difficult to talk to dying residents and their families.[22]

One study compares the frequency of grief symptoms in professional caregivers with that of bereaved family caregivers of persons with dementia using the Texas Revised Inventory of Grief (TRIG), a validated instrument to standardize grief measurement. These two groups of caregivers have similar score for nine symptoms, including missing the person, being reminded of the person by things in their surroundings, becoming upset when thinking about the person, being preoccupied with thoughts about the person, finding it painful to recall memories of the person, hiding tears when thinking about the person, not accepting the person's death, feeling that the death was unfair, and being unable to accept the death.[15]

Qualitative studies also reflect the impact of death on staff emotions. For example, seven qualitative studies describe staff members crying. [13,15,21-23,25,27,33] One manager explained "the day they don't cry is when they don't work here, because they have got to care….[p]eople wouldn't be doing the job properly if they weren't emotionally involved."[25] This, however, was a minority view among managers: most did not encourage crying.[25] Several staff members describe the unacceptability of crying on the job, particularly for long periods of time.[21] Staff are expected to "be strong" and can go and cry on their own time.[13] CNAs reported that "caring for a dying person is emotionally draining, distressing, sad, stressful, and makes them feel helpless."[23]

Factors that Exacerbate Grief

Quantitative studies found that staff reporting longer and closer relationships with residents report more grief symptoms (Spearman rho = 0.32, $P < 0.001$; rho = 0.24, $P = 0.001$).[15,33] Staff who were unprepared, "emotionally or in terms of the information they had about the patient's condition" also experienced more grief symptoms (explains 8% of difference in grief, independent of all other factors).[15] The qualitative studies show that difficult deaths for staff to handle include those that are unexpected[29] and those that are prolonged,[13,21,22] especially if the pain cannot be adequately controlled.[29] In most of the qualitative studies, staff explained how painful it was if they felt that they had insufficient resources (such as time) for dying residents' care.[22-25,28,29]

DISCUSSION

As noted above, this is still a developing field of literature. To date, there are a limited number of studies published in the field. Most of the studies are qualitative, and all quantitative and mixed methods studies rely on cross-sectional analysis. However, this subject is extremely important, because the grief suffered by long-term care staff has an impact on their personal well-being and their ability to provide quality care. More research is needed.

General Gaps in the Literature

Only one quantitative study examines the somatic symptoms associated with grief in the long-term care (LTC) setting,[17] and discussions of somatic symptoms in qualitative papers are limited to sleeplessness and anxiety. The scientific study of grief clearly shows that death of a loved one has an impact on mortality, morbidity, and healthcare expenditures of the bereaved. None of the quantitative or qualitative studies examines the impact that these deaths have on the mortality, morbidity, or health spending of the bereaved.

Many of the quantitative studies are done through a lens of burnout and turnover of LTC staff. The focus is not on the well-being of the staff. They do not consider the long-term or even short-term health impact on staff that have burned out or whether working in LTC might be hazardous to one's overall health. The qualitative studies tend to focus on staff well-being to a greater degree, but they largely focus on emotional well-being and its impact on staff's ability to function. They examine best practices that can alleviate their stress and better handle their grief. However, to a large degree, the focus is also on their abilities as caregivers.

Implications and Areas for Future Research

Before analyzing a problem, one must first document that the problem exists. To the best of our knowledge, this is the only systematic literature review focused on LTC staff grief and including both quantitative and qualitative studies. It shows the state of the literature today, and it establishes evidence of the need to analyze a serious issue. This review shows evidence of the toll that grief can take on LTC staff. Turnover among LTC staff, particularly nursing assistants, is a grave problem, and the association between burnout and turnover is well-documented.[26] However, there is a dearth of literature directly examining the impact of grief on LTC staff. For that reason, this systematic review extends back to 2000. Since the experience of grief among LTC staff has not changed extensively during that time, we believe that older studies remain relevant and contribute to our understanding of the subject.

Longitudinal studies in this area would be beneficial. They could establish whether burnout is caused by grief, instead of merely associated with it, and they could document health outcomes of bereaved long-term care staff. This could provide guidance for developing effective interventions.

More broadly, there is room for additional studies that focus on the impact that this sort of work has on the health of nursing home staff. Quantitative studies could examine mortality, morbidity, or healthcare utilization of LTC staff, as compared with the general public. This could be done through longitudinal studies that followed individuals over time. Qualitative studies could also better examine the physical health of nursing home staff, particularly those that suffered from losses both inside and outside of the facility. They could conduct a more detailed analysis of the physical health of nursing home staff after traumatic incidents in their personal and professional lives.

Limitations and Potential Biases

The qualitative studies almost universally included many best practices, such as descriptions of the study design, including methodology, sample size, sampling methodology, setting of the study, descriptions of interview questions, duration of interviews, etc. They also did an excellent job clearly reporting techniques for analysis, the themes that were found, and illustrative quotes. These are among the most frequently reported qualitative best practices.[37] On the other hand, they generally did not report many characteristics about the interviewing team, and few of them reported detailed demographic data, although they consistently described participants' professions and years of experience. They also generally failed to note the number of individuals who declined to participate, and none of the studies engaged in follow-up interviews to clarify themes or obtain feedback on their findings.[37]

The biggest limitation on the quantitative studies is that they are all cross-sectional in nature, which means that causation cannot be established; however, they do establish strong associations between deaths of residents and grief symptoms. These include both somatic and emotional symptoms, and they also include symptoms such as detachment/depersonalization of residents, which can affect resident care. They also included detailed descriptions of their recruitment methods and the percent participation levels. While all of the purely quantitative studies collected data using validated scales and gave a detailed description of their data analysis, one of the mixed methods studies did not clearly explain how the questions were derived for the quantitative section or thoroughly explain the data analysis technique.[23] In addition, both mixed methods studies failed to provide detailed demographic information about the participants.[22,23]

These studies are also susceptible to several forms of bias. First, they are all subject to selection bias. LTC staff that agree to participate in a study related to staff grief may be those who are the most bothered or stressed by the grief. Thus, these studies may tend to exaggerate the presence and impact of grief. In addition, LTC facilities that participate may be those that are more proactive at caring for their staff and therefore not representative of all facilities. This might affect the ways in which staff are permitted to express their grief and therefore the effect that grief might have on them. In addition, if participants doubted assurances of confidentiality, response bias could occur. Furthermore, most studies had geographic limitations: with one exception, [33] all studies were limited to participants in a single region. Finally, like many areas of research, publication bias may be an issue here. A study that does not find that grief is a problem, or a study that finds no evidence of an association between grief and burnout, may be less likely to be published.

CONCLUSION

Evidence from both quantitative and qualitative studies indicate that LTC staff grieve after the death of a patient. Depersonalization burnout is associated with staff grief, and there is evidence that personal accomplishment and/or job satisfaction may mitigate burnout. In addition, multiple qualitative studies indicate that staff frequently do not receive the resources or training to deal with grief. This grief is reduced when staff are encouraged to see the rewards in helping through an extremely difficult process. Leadership should ensure that staff have the needed resources and support.

TABLE 2.1 - PRISMA Systematic Review of staff experience with resident dying and death: Databases used in review and Number of Hits

Ageline (49)	CINAHL (31)	PsycInfo (29)	MEDLINE (29)
MEDLINE (full text) (29)	Complimentary Index (20)	Academic Search Complete (19)	SocINDEX with Full Text (12)
Supplemental Index (12)	Gale Academic OneFile (11)	Gale OneFile: Health and Medicine (10)	Abstracts in Social Gerontology (9)
Family & Society Studies Worldwide (9)	Health Source: Nursing/Academic Edition (9)	Directory of Open Access Journals (7)	Psychology and Behavioral Sciences Collection (6)
Consumer Health Complete-EBSCOhost (6)	Advanced Placement Source (5)	Science Direct (5)	Social Work Abstracts (4)
Gale General OneFile (3)	Vocational and Career Collection (2)	Newspaper Source Plus (2)	ERIC (2)
Professional Development Collection (1)	British Library EThOS (1)	Marquis Biographies Online (1)	Education Research Complete (1)
Global Health (1)	Health and Psychosocial Instruments (1)	Gale OneFile: News (1)	J-STAGE (1)

FIGURE 2.1: Prisma Statement

PRISMA 2009 Flow Diagram

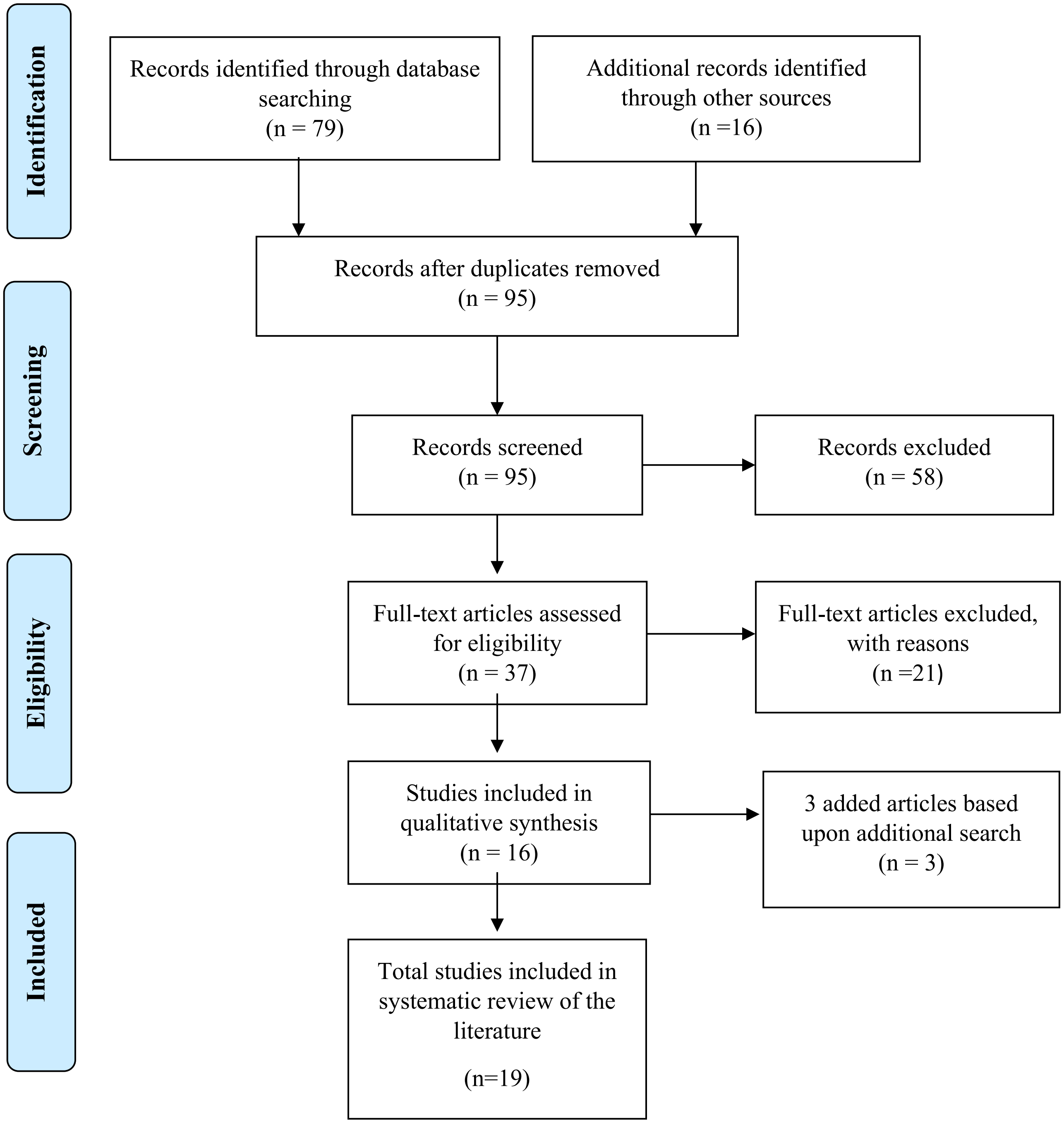

TABLE 2.2 - PRISMA Systematic Review of staff experience with resident dying and death: Characteristics of Selected Qualitative and Mixed Methods Reports / Topic and Sample

Topic	Sample
Mixed Method Studies, Qualitative Section	
Burden of resident death on staff	*Participants*: N = 17 staff from 3 LTC facilities with different sizes; Purposive sampling; Age range: 26-52 years, Experience: 6 months-16 years. *Analysis*: Qualitative content analysis, responses informed quantitative survey *Source*: Jenull & Brunner 2008[22]
Experience caring for dying resident	*Participants*: n=35 (nursing assistants) from 2 facilities.4-8 person group interviews of staff that cared for residents that refused life-sustaining treatment. *Analysis*: Thematic analysis of open-ended discussion question responses. *Source*: Burack & Chichin 2001[23]
Qualitative Method Studies	
Experience Caring for Dying Resident	*Participants*: n = 5 RNs (1+ year of experience) from one facility. *Analysis:* Case study, thematic analysis of unstructured interviews & reflective journals *Source*: Irvin 2000[24]
Grief & Support Needs in LTC	*Participants*: n=400 LTC stakeholders: 100 initial interviews with LTC managers at 100 sites & 300 case study interviews at 12 sites *Analysis:* Case study, thematic analysis *Source*: Katz et al 2001[25]
Staff / Resident bond	*Participants:* n=26 (18 CNAs, 6 LPNs, 2 RNs), 5+ years employed *Analysis*: Thematic analysis of interviews from Jewish and Catholic LTC facility, purposive sampling to ensure diversity of participants *Source*: Moss et al 2003[26]
Staff Response to Death in LTC	*Participant*: n = 1 (activities director in LTC) *Analysis*: Multiple ethnographic interviews & informal conversations Case study, narrative analysis of data, follow-up interviews, additional analysis *Source*: Black & Rubenstein 2005[27]
Impact of Death in LTC	*Participants*: n=10 (3 LTC staff & 7 residents), interviewed within 24 hours of a resident death, cognitively impaired excluded *Analysis*: Thematic analysis of interviews, phenomenological methods *Source*: Chroinin et al 2011[28]
Experience with death and EOL Care	*Participants*: n=11 (residential care aides). Volunteers, mean age: 48, live-in setting, minimum experience of 1 year. English only. *Analysis*: Thematic analysis of interviews, categorization & sub-themes *Source*: Funk et al 2014[29]
Workplace policy	*Participants*: n=10 administrators/supervisors in 10 LTC facilities, that were randomly selected from 31 available facilities in Cincinnati area. *Analysis*: Comparative thematic analysis of interviews by 2 researchers *Source*: Source: Chahal et al 2015[20]

Grief needs of LTC Staff	*Participants*: n=9 LTC nurses & social workers with 3+ years of experience from 2 facilities in Ontario, Age range: 20-54 *Analysis*: analytic induction of interviews to derive categories of grief needs *Source*: Marcella & Kelly 2015[13]
Needs of LTC Staff Providing EOL Care	*Participants*: n=22, 3 focus groups: nurses & assistants, manager, & physicians. Purposive sampling to ensure diversity in participation. *Analysis*: Thematic content analysis by four coders to ID 17 categories, part of larger action research project. *Source*: Bukki et al 2016[30]
Staff Grief	*Participants*: n = 25 staff volunteers (12 Health care aides and 13 nurses from multi-unit LTC facility, mean experience: 12 years) *Analysis*: Thematic and conceptual coding of interview transcripts *Source*: Funk et al 2017[21]
Distress and End of Life	*Participants*: n=16 (2 managers, 4 nurses, 10 assistants, Experience: 4 months-28 years); 6 randomly selected facilities invited, 4 participated. *Analysis*: Thematic analyses of interviews using critical incident technique Source: Young et al 2017[31]
Observation of dying process	*Participants*: n = 707 (nurses, nurse aides, & social workers) from 52 facilities *Data*: Online and paper surveys. *Analysis*: Thematic content analysis by multiple coders to ensure concurrence. *Source*: Cagle et al 2017[32]

LTC: Long-term care. EOL: End of Life. This table focuses on the qualitative section of mixed methods studies. Those studies also have quantitative sections which are described in Table 3.
Notes on methods:
Qualitative content analysis is a method of coding and thematic analysis of interview or focus group transcripts.[38] Case studies are in-depth study of a small number of cases.[39] Purposive sampling involves selecting individuals with specific characteristics to ensure diversity.[40] Thematic analysis or thematic content analysis: analyzing data for common themes.[41] Critical incident technique involves focusing the interviews on a defined incident, such as caring for a resident who died.[42] Phenomenological methods involve focusing on a distinct experience.[43]

TABLE 2.3 - PRISMA Systematic Review of staff experience with resident dying and death: Characteristics of Selected Quantitative and Mixed Methods Reports / Topic and Sample

Topic	Sample:
Mixed Method Studies, Quantitative Section	
Burden of resident death on staff	*Participants*: N=894 from 49 LTC facilities (49% response rate) *Data*: Survey results, stratified by position (nurse/non-nurse) *Analysis:* Descriptive stats, non-parametric procedures, Mann-Whitney test, Wilcoxon test, Spearman correlations *Source*: Jenull & Brunner 2008[22]
Experience caring for dying resident	*Participants*: n=35 (nursing assistants) from 2 facilities. *Data*: 4-point & 5-point Likert scale surveys, given to all participants twice *Analysis*: Descriptive stats, analysis of survey results *Source*: Burack & Chichin 2001[23]
Quantitative Method Studies	
Grief, Support, Burnout, Detachment	*Participants*: n=220 (140 CNAs & 80 HHAs) from 3 NY LTC facilities *Data*: 2 Validated scales TRIG (grief) & MBI (burnout). Also 2 additional questions to assess grief avoidance behavior. *Analysis*: Descriptive stats, bivariate correlation, hierarchical regressions *Source*: Boerner et al., 2017[14]
Grief Symptoms, Staff Preparation	*Participants*: n=220 (140 CNAs & 80 HHAs) from 3 NY LTC facilities *Data:* TRIG scale for CNAs, HHAs, and pre-existing TRIG data from families *Analysis:* Descriptive stats, bivariate comparison, hierarchical regression, χ^2 test *Source*: Boerner et al. 2015[15]
Grief as Predictor of Burnout & Detachment	*Participants:* n=380 LTC staff from 11 facilities near large Midwest city *Data*: Validated scales: TRIG (grief), HG (personal growth from grief), PWB (perceived well-being), NHNAJSQ (job satisfaction questionnaire) *Analysis:* Descriptive stats, 6 stepwise linear regression models. *Source*: Anderson et al., 2011[17]
Grief & other predictors of burnout	*Participants*: n=136 CNAs, 12 rural KY LTC facilities, 50.4% response *Data*: Validated scales: TRIG (grief), HG (personal growth from grief), PWB (perceived well-being), MBI (burnout). *Analysis:* Descriptive stats, multiple regressions *Source:* Anderson et al. 2008[16]
Grief Symptoms in LTC Staff	*Participants*: n=203 staff, 6 geriatric care orgs in 3 states, 86% response *Data*: Surveys, including deaths experienced in past month, grief symptoms, relationship with deceased, & available or desired support. *Analysis:* Descriptive stats, χ^2 or non-parametric tests, linear regression models, Pearson product-moment coefficient to detect correlation *Source:* Rickerson et al. 2005[33]

TRIG: Texas Revised Inventory on Grief.[35] MBI: Maslach Burnout Inventory.[34] HG: Personal Grief Subscale of Hogan Grief Reaction Checklist.[44] ICG: Inventory of Complicated Grief.[45] PWB: Perceived Well-Being Scale.[36] NHNAJSQ: Nursing Home Nurse Aide Job Satisfaction Questionnaire.[46]

TABLE 2.4: PRISMA Systematic Review of staff experience with resident dying and death: Commonly Reported Responses by Staff to Resident Death

Source	Stress/ Distress / Emotions	Familial Bond With Residents	Grief Severity Increased by Other Factors*	Crying or Hiding Tears	Emotional Detachment from Residents	Specific request for help coping
Irvin 2000	✓	✓	✓		✓	
Katz 2001	✓	✓	✓	✓		✓
Burack & Chichin 2001	✓	✓	✓	✓		
Moss 2003	✓	✓				
Black & Rubenstein 2005	✓	✓		✓		
Rickerson 2005	✓			✓		
Jenull 2008	✓		✓	✓		
Anderson 2008					✓	
Chroinin 2011	✓	✓	✓			✓
Anderson & Ewen 2011					✓	
Funk 2014	✓	✓	✓		✓	✓
Chahal 2015	✓	✓				
Marcella & Kelley, 2015	✓	✓	✓	✓	✓	
Boerner 2015			✓	✓		
Bükki 2016	✓		✓			
Funk 2017	✓	✓		✓	✓	✓
Boerner 2017					✓	✓
Cagle 2017	✓	✓	✓			
Young 2017	✓	✓				✓
Total	**15**	**12**	**10**	**8**	**7**	**6**

*Factors increasing grief severity (# of studies): prolonged or painful death (6), surprise death (4), feeling by staff that they did not have ample resources to give quality care (8). In multiple studies (2-3), grief exacerbated by lack of memorial, insufficient training, & close proximity to other deaths/trauma. Mitigating factors: job satisfaction, time with residents, & "good" deaths.

CHAPTER 3

GRIEF IN LONG-TERM CARE: A QUALITATIVE CONTENT ANALYSIS OF STAFF INTERVIEWS[2]

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[2] Brown-Brundage, A.A., Skelly, C., Clack, L., O'Rourke, P., Miles, TP. To be submitted to the *Journal of Pain and Symptom Management*.

ABSTRACT

Context: There is growing evidence of the grief experienced by LTC workers due to resident deaths. More evidence is needed to understand this grief and the factors that can exacerbate or mitigate it.

Objectives: To gain insight into and provide evidence of the grief symptoms experienced by long-term care (LTC) staff as a result of loss and the factors that mitigate or exacerbate those symptoms.

Methods: This paper consists of a qualitative content analysis (QCA) of seventeen interviews conducted with LTC staff and the chaplains that work with them in the LTC setting. A detailed Codebook was created detailing each code to be used, and each interview transcript was independently coded by two coders. The coding frame results were presented using a series of illustrative text matrices, which provided examples of each code, and case studies, which took a more in-depth look at five illustrative cases.

Results: Staff suffered extensive grief symptoms. In every interview, staff described emotional symptoms of grief, and in 14/17 interviews, they described crying. Many staff empathized with grieving family members, sometimes reliving their own grief experiences as they watched family members grieve. Many staff members experienced symptoms of burnout or found themselves dwelling on deaths. A minority of staff also experienced physical symptoms of grief. Cumulative loss, or losing multiple people (family members, residents, or some combination) within a short period of time exacerbates grief symptoms. Grief symptoms are also frequently exacerbated when staff have to deal with difficult interactions with family members, when they have particularly close relationships with the deceased, or when they have to deal with excessive

paperwork or bureaucracy. Several staff members discussed difficulties with angry or abusive residents, but they were generally sympathetic towards such residents, explaining that those residents were affected by their declining condition and could not help their actions.

Conclusion: Most staff members felt that it is necessary to develop a familial relationship with residents to provide a high quality of care. This helps them to find meaning from their work and feel a sense of personal accomplishment; however, it also causes then to grieve when residents die. To mitigate grief symptoms, LTC facilities should provide a supportive environment for staff and as many resources as possible to manage their grief and to provide the best possible care for their residents.

INTRODUCTION

Long-term care staff must repeatedly care for residents and watch them die. Many of them have also experienced losses in their personal lives. However, few studies fully document the impact of grief as described by the staff members. Through a thorough qualitative content analysis of seventeen interviews with staff from diverse settings, this study documents the grief that staff experience and the factors that exacerbate it.

RESEARCH QUESTIONS

1. How do long-term care (LTC) staff manifest their grief following deaths of their residents, family members, and close friends?
2. How are LTC staff affected by cumulative losses of family, friends, and/or residents?
3. What practices or experiences exacerbate or mitigate staff grief and stress within LTC?

RESEARCH PURPOSE

The purpose of this study is to gain insight into and provide evidence of grief experienced by staff and factors that may exacerbate or mitigate it. This paper analyzes extensive interview data obtained in long-term care (LTC) facilities to gain a deeper understanding of the impact of grief and the factors that can ameliorate the environment for LTC staff. It also examines the experience of cumulative loss that is common among LTC staff.

BACKGROUND

Between 2016 and 2019, the University of Georgia Project team (the team) conducted interviews with LTC staff, residents, and family members as part of a long-term care (LTC) facility quality improvement project funded by the Centers for Medicare and Medicaid Services

Civil Money Penalty Reinvestment Fund. As a result of that project, the team created best practice guides for bereavement care and end of life planning targeting staff, residents, and family members in LTC facilities. I have been a member of the team since the project began in 2016.

Before conducting the interviews, we obtained approval from the University of Georgia Institutional Review Board (IRB). We conducted interviews in nine LTC facilities in southern Georgia in 2016 and 2017. In 2019, we conducted follow-up interviews in two of the LTC facilities. I personally conducted 15/17 interviews that are analyzed here, either individually or jointly with another team member. I have written permission from the P.I. of the project to conduct an in-depth analysis of this data and publish the results. I will not publish any personally identifiable information (PII) from the interviewees.

METHODS

I began this project by selecting interview transcripts for analysis using the "purposive sampling" technique. Since my research purpose was to address the grief of LTC staff, I selected only interviews of LTC staff and the chaplains who work with them, and I chose interviews in which staff gave thorough, descriptive answers to questions. I was especially interested in interviews where staff recounted personal experiences of themselves and their colleagues. After carefully reviewing the available data, I selected seventeen interviews. Most interviews were individual interviews, but a few were group interviews. The total number of interviewees was 28. As noted earlier, I had personally conducted fifteen of the seventeen selected interviews (26 total interviewees), either alone or jointly with another team member.

Because I am analyzing previously obtained interview data, I selected qualitative content analysis (QCA) as the best method for the analysis.[38] The first step in the QCA process was to create a coding frame. Initially, I had considered five potential research questions, although in the end, I decided to narrow my scope and focus on the three questions that my interview transcripts most thoroughly addressed. Because I had initially considered five questions, I began by selecting five domains for my coding, one for each potential research questions. I had previously gained expertise in this area through (1) my extensive experience conducting interviews and (2) my experience conducting a thorough systematic review of the relevant literature. I used this expertise to make a list of relevant categories within each domain. For each of these categories, which will also be referred to as codes, I created a detailed definition. In many cases, my main coding category included subcategories listed within that definition. For example, one code within the "grief symptoms" domain related to crying, and was used anytime a staff member described one of three subcategories: (1) crying, (2) holding back/suppressing tears, or (3) the inability to cry. Each domain included an "other" code, to be used for material that seemed relevant to the domain but did not fit directly into any of the defined codes. The final Codebook, with a detailed description of each Code, is listed in Appendix A.

The next step was to test out the codes through a process called "pilot coding." This is a process through which the researcher tests out her codebook on a small set of the material and makes any needed changes to the codes. I selected three interviews for the pilot coding process.

The first step in the pilot coding process was segmentation. This process involved carefully reading through the interviews and selecting sections (segments) that were potentially relevant to my research questions. Each segment included at least one question and all subsequent discussion related to that question. The segments varied greatly in length: some were as short as ten lines, whereas others spanned multiple pages. These segments were the sections that would be evaluated during the coding process.

Next came the actual coding process. I carefully read through each segment, and when I located text that fit within a code, I highlighted that text within the Word document and then entered the segment number and line number(s) into a spreadsheet. I color coded my highlighting, so that codes from different domains appeared in different colors. To ensure objectivity and consistency, a second coder independently coded each interview. This coder was a graduate student that had no prior knowledge of the material, which minimized the chance of any subconscious bias. After we each completed our coding, all codes were discussed and agreed upon by both coders. This is known as "coding to agreement." Our discussions led to various changes and clarifications to the codes within the codebook.

Once the three initial interviews were coded to agreement in all five domains and all necessary changes were made to the codebook, I began coding the remaining interviews. This process was similar to the initial coding. I coded all interviews, and I had a second coder independently code them to ensure consistency and objectivity. After independently coding each interview, we scheduled virtual meetings to compare our codes and discuss any discrepancies.

I presented my results in two sections. In the first section, I presented my coding frame. Due to the large amount of data, I elected to use text matrices to describe most of my material. Each text matrix included illustrative quotations followed by a description, code, or subcategory. I also included a short textual summary of my findings for each code. I presented all codes listed in my first two domains. For my third domain, which had a large number of codes, I did not discuss codes that were used in fewer than three interviews.

My second results section includes a more in-depth description of five selected cases (interviews). These cases were selected because they provided vivid examples of multiple codes within each of the domains. Finally, in my Discussion section, I identified commonalities in the interviews, and I examined the relationships between the different codes to determine whether certain codes frequently appear together. Based on my results, I made several observations about the experiences of LTC staff.

RESULTS

Part 1: Coding Frame

This section summarizes the coding frame that was developed, with illustrative examples.

Domain 1: Grief

Emotional Response to Grief

In all seventeen interviews, staff described emotional symptoms that they experienced personally or that they witnessed in other staff members following deaths. Subcategories of this code include sadness, anger, missing a person, describing a death as “traumatic,” suppression of emotions, etc. A detailed description of the code is included in Appendix A. Severity of the emotional symptoms varies greatly. In most cases, interviewees discussed these symptoms in relation to both losses of residents and losses that many of them have experienced within their personal lives. For example, two staff members had a child die while working, and a third one experienced the death of a life partner, which left her as the single mother of a little girl who was also coming to terms with the loss of her father. They often compared the losses of their residents to personal losses. Most described sadness or emotional devastation. In 13/17 interviews, staff described grief after losing a resident with whom they developed a close relationship. The table below provides several examples of emotional staff responses to grief.

Emotional Response to Grief

I really miss, you know, coming in in the mornings, and he’d see me and he’s say, “hey baby, how are you doing today?” You know, I really miss that. And it’s the same with my mother. You know, something happens and you think about something and you’re like ‘”oh, I need to call mama.” But mama’s not there.	Missing residents just as one misses deceased family members
You do grieve at home as if you were grieving for someone in your family because that’s what they become to you. Your family. So, it’s a challenge when you lose a person that you feel encouraged you to be a better person. You realize that they were a great person, and think wow, how do I deal with this?	Sadness due to the loss of a resident who had an impact on one’s life
We had an associate that passed away…and she died unexpectedly. Young woman, and it was a difficult situation for everybody and probably one of the most traumatic this facility has ever experienced. Me personally…I'll never have that close a work friend again.	Trauma of losing a coworker
[S]ometimes you can’t approach people because they’re just in an angry phase all the time. You can do little things like help them out, “let me get those medicines for you.” I’m going to help you, I don’t know, I’ll give those medicines, just to like maybe help them a little bit more.	Grief expressed through anger
When you start admitting thirty year olds and you’re like “dang, 27” oh, and then I get a referral 28 year old on the ventilator that has an unborn-. I’m like “oh that is a straight no. How am I supposed to, that child is gonna be my issue.” So, I, I realize there are things that I would’ve thought “oh I would never have to entertain these, these things,” but lately I’ve been entertaining some crazy moments. And I, I feel sometimes it’s my ethics, I would probably say I have to have a very strong ethics. But I also would say “Don’t cry about it.” I get frustrated with it, there’s a lot of frustration.	Frustration due to heart-wrenching decision
[W]e have feelings, but we know we’ve gotta, like you said, suppress in some ways to be able to keep functioning, but it doesn’t mean you feel any less when you’re in that role and someone’s died.	Need to suppress one’s feelings

Empathy with Grieving Families

In eleven interviews, staff members described their empathy with grieving family members. I use this term when staff react emotionally to and/or vicariously experience the grief symptoms of families, often because they have had similar experiences with their own family members.

Empathy with Grieving Families

When my Mom passed, it was hard for me to come back, and I remember the first time a female passed after my Mom passed, and I was at work, and I thought I was OK, and I saw her daughter come in and break down, and she, and I was bawling as bad as the daughter was, because I knew, I knew just what she felt. I knew exactly what she felt.	Staff reminded of own grief experiences
I’ll never forget this one, this one death that I had when I was working. It was a lady, she was an elderly lady. And it was her son, and he was a big guy, I mean, he must have been like 300 pounds. He was just a big guy. And when he, and I remember I never forget this image. Once she died, and he, he was there with her, he was, you know, with her when she was not doing well. But once she passed, he came out in the hallway, and he was on one knee, and he was just…on one knee, he was just broken, his heart broken, just crying. But you know, to see him, a big guy like that, on one knee holding his chest, it was just like, the pain was so great that it brought him to his knees… I always think about him, even when I’m calling someone to tell them that they’re family member has taken a turn for the worst, that they may want to come to the hospital or the facility,	Staff moved by the visible emotions of family members
And it took an impact on the whole building, because she’s a jolly perky person. But when she was down, it’s like we *all* felt her pain. And we do go through that, ‘cause we are close-knit here. A lot of us are very close and when one hurts, we all hurt. So we rallied and did what we needed to do to get her through that hard time. We had a lady lose her son here, in a freak car accident. And that was, that was really hard. That was real hard. You know, ‘cause seeing that we all got children. We think of the ‘what if.’ We think about the pain that she was going through. So a lot of times we all had to live through it, to keep her going. And it was, it was, that was a hard, now that was hard for us. We, we went through that; she didn’t go through that. *We* went through that.	Impact of witnessing a fellow staff member experience the loss of a family member

Crying

In 14/17 interviews, staff members discussed crying, suppressing tears, or the inability to cry as a result of loss. In two cases, the interviewees broke down into tears during the interview. For example, in discussing her first experience at having a close resident die, one staff member explained that she was hurting but “could not even cry” even though she thought she would feel better if she could. She also described the annual memorial ceremony, where staff and family members cry together as they show pictures of the deceased residents in various life stages.

Numerous staff members discuss becoming attached to residents and crying and consoling each other after their deaths. One staff member explained that staff and residents frequently come into her office and close the door when they are upset. She went on to describe one staff member that broke into tears, saying that she had felt like choking a difficult resident, but had instead come into the office to talk.

Crying	
I still get tears when I think about it, because it was just…it was so moving to me. [Staff member is referring to experience of seeing grieving son fall to his knees and cry].	Crying as a result of empathy with grieving family members
I got just as close to her mother as she was. I think I cried just as much when her mama died as she did.	Familial relationship with deceased
It is so touching, you know. The staff are in tears sometimes, and the family members are. It just brings them back alive just to see, you know, the pictures interacting and activities and so forth.	Staff and family crying together at memorial service
I have seen some staff get so attached, they cry more than the family members.	Staff attachment to residents
I'm just a super sensitive person, and I've always heard that tears cleanse the soul. So, a lot of times I do cry freely.	Staff member who cries frequently
You do get attached, and, you know, we cry, and we console each other when we've lost somebody.	Crying and consoling each other after loss
The loss of the human resource director last year was probably the best example I can give where I called everybody, myself in tears, [I] could barely speak to tell them that night when I found out that she had passed away.	Grieving the loss of a fellow staff member

Dwelling on Death

Seven interviews discussed dwelling on deaths. I use this term to refer to cases in which a staff member continues to think about a death over an extended period of time, has a difficult time recovering from a death, or explicitly states that that he/she has dwelled upon the death.

Dwelling on Death

But I remember the very first person that, that I had to die, was in Pensacola in 1992. Because we talked, and I was in her bed and I had my little arm around her, and she was talking to me about her husband and her dancing. And she was, you know, said “I would just love to dance one more time” and so, I said, well what was your favorite song, and you know, she told me, and I said well let me just hum that. So you know, we can pretend like we’re dancing. But, golly that was twenty something years ago, but, I can see her to this – don’t remember her name – but I can see her to this day.	Memory of first resident death more than 20 years prior
I’ve gotten to the point where you cannot dwell as much on it, but there are a few that I’ve dwelled on. Like, there’s a patient that I took from another skilled nursing facility, but I was the admissions director, or the regional, um, director, and I, I know this patient. But this patient just passed, uh, recently just out of the blue. Just completely was out of left field. So it made me wonder. But he had no fam-, well, he did have a son, but what I gather for a very long time they were completely estranged. No contact, and so we sat, and we tried, we sent the police over to the, to the son’s house. No one was there. No one knew him.	Dwelling on the death of a resident that had no grieving family
[G]rief can take a hold of you and you forget. It can consume you to the point that. You don't know what time of day it is what day of the week what time of the year. And then you wake up one day and it's October. It's a slow process. Here we're three and a half years in our in our grief journey because it is. Exactly a journey. And I still don't know what next year is going to look like for us. That's scary.	Being totally consumed with grief for years due to the loss of a life partner

Physical Symptoms

In four interviews, staff discussed physical symptoms, ranging from physical exhaustion to more serious symptoms. One staff member described grief manifesting itself as pain the knuckles, pain in the back, pain in the neck, migraines, digestive issues, and a greater susceptibility to illness. She also explained that physical and emotional symptoms of grief can exacerbate each other. One chaplain explained that some of his grieving clients have complained that grief affects their physical health.

Physical Symptoms of Grief

I’ve noticed…these weird little pains you get…grief can show up when your knuckles hurt or your back hurts or your neck hurts. I’ve had probably more migraines in the last three years…digestive issues: more susceptible to viruses and things.	Physical pain due to grief

When I called her, I was so upset I couldn't breathe.	Physical reaction to a death
I've notices over the past few years, when I am physically tired the emotional stuff is compounded and when I'm emotionally tired the physical stuff is compounded.	Compounding effect of physical and emotional symptoms

Burnout

Burnout and turnover are serious and frequent problem among LTC staff and the chaplains that work with them. In fact, there are several quantitative and mixed methods research papers that focus on measuring burnout.[14,16,17,47,48] These papers adopt the Maslach Burnout Inventory (MBI), a validated scale, to measure burnout among staff members.[34] This inventory includes three scales to measure different forms of staff burnout: depersonalization, emotional exhaustion, and a lack of the feeling of personal accomplishment. Here, I have examined the interviews both for explicit references to burnout and for descriptions of items on the Maslach Burnout Inventory. Twelve interviews either make an explicit reference to burnout or describe one or more scales on the MBI.

Explicit References to Burnout by Staff

In seven interviews, the interviewees explicitly used the term "burnout," "burned out," or "burns you out."

Explicit References to being "burned out"	
I call people like them and say 'look man, I'm struggling." Yeah, chaplains call other chaplains to say "Yeah, man, I'm struggling. I'm burned out." So yeah, we get burned out, and we get to a place where we say, you know, I'm at, I'm at 434 deaths, that's just hospice, in 10 years. That does not include the family, friends, clergy members. It gets to be overwhelming, and when you do it full time, as I do, um, it consumes you after a while. It just literally consumes you. And after 10 years, yeah, I'm looking to make a change. It just kind of burns you out after a while.	Frequency of burnout among chaplains
I got burned out. Um, I had a nervous breakdown when my son died. I was going through a lot then. Uh, I was out for a little while, then I came back and, um, I was the CNA supervisor for a few years. And you know, if you're over 20-something CNAs,	Burnout following the death of child

and you're trying to deal with the death of your child, and, um, my father died around that time. And my son, and my stepfather, and my baby brother. So all that was happening at one time, and I did get burned out.	and other family members
Now this in my 11 years being here, of having to do certain things. So, yeah. I have had to call the police on an employee for resident abuse, because they was [sic] burned out. I had an incident where, I walked around the corner and this CNA was hitting a resident with a belt, because the resident had hit her with the belt.	Physical violence resulting from burnout

Maslach Burnout Inventory

The Maslach burnout inventory describes three scales: depersonalization of residents, emotional exhaustion, and feelings of personal accomplishment. My coding attempted to capture examples of all three scales. In addition to examples of depersonalizing residents (e.g. detaching oneself from them) and emotional exhaustion, we also noted cases where staff members reported feeling a sense of accomplishment, or feeling that the job is rewarding, as a behavior that counteracts burnout. There were twelve interviews that described one or more scales on the Maslach burnout inventory, and the following paragraphs contain examples of reports from staff that illustrate these scales.

Depersonalization/Detachment from Residents

The depersonalization scale measures the degree to which staff develop and impersonal relationship towards residents. Depersonalization is a risk when there is development of relationships with and attachment to residents: some staff expressed the sentiment that due to past pain (or witnessing such pain in others), they would not allow themselves to become too attached to residents. For example, one staff member stated:

> But when she got sick and she died, I told everyone that I would never get attached to another resident like that again. And I have not.

Attachment to residents is paramount to the provision of quality care. The more impersonal the relationship becomes, the higher degree of depersonalization. None of the staff members with whom we spoke expressed complete indifference to the residents, as one would see in the most severe cases of depersonalization. In fact, most explained that attachment to residents is inevitable for a caregiver, and that they suffer when residents die.

> What I don't understand is how they want you to *not* get attached to someone. When you lose those people that you become attached to, it's hard to come back to work. Now, my first baby—I only had three babies – one of 'em is still here. Now, when my first baby passed, you know, when she was out to the hospital – she didn't pass here; she passed at the hospital – I remember going out there, and it'd have you doing that. It'd have you going to the hospital to go see 'em. You got to make sure the aide is there taking care of 'em. You, I mean, it just--but to some of, you know, we thinking different, like "D---, my baby just passed." You know, that's whole thing about getting attached.

Emotional Exhaustion

Another scale on the Maslach Burnout Inventory is emotional exhaustion. Staff and chaplains often become exhausted from dealing with death and other stressors in long term care.

> That's so important if you have four significant deaths, who's taking care of you, and are you letting people in or are you just handling it, just going through day by day? And all of us can ask ourselves that question. You get fatigued, you get, you get fatigued, not just about death but so many things.

Personal Accomplishment

The final scale on the Maslach Burnout Inventory relates to personal accomplishment. When staff feel that they are accomplishing something positive or that their work is rewarding, meaningful, or satisfying, it can counteract burnout. Six of the staff members with whom we spoke expressed this sentiment.

> I don't think you get conditioned to [death], but you get where you say did, I [did] everything that I could do for this to be really good for [the resident] and really good for their family. And sometimes you work with people that show you what that looks like. So, you get better and better and better at it, and I think then you begin to look back and think did I do everything I could to make this a good death for them. And when you know you did, there is a sense of accomplishment about it: there aren't a lot of things you can control about in the life but that is one of the things you control.

One staff member described her work as having a “higher purpose,” and explained that it puts personal problems into perspective. An administrator explained that he is motivated to continue to do his work because it gives him the opportunity to exceed expectations with regard to long-term care.

Domain 2: Cumulative Loss

In eleven interviews, interviewees discussed the impact of cumulative loss, or multiple losses in a short period of time. The “short period” is not defined by a specific amount of time, but instead based upon the interviewees’ perception that the deaths occur in a short period. All interviews discuss multiple losses, but when interviewees described suffering from multiple losses in succession, I categorized this as a cumulative loss.

Cumulative Loss	
I’m, my oldest friend, this week, known him 46 years, I have, it’s been a very difficult week, because I’ve, in, in the last year, I’ve lost four extremely, uh, close people, including as I was mentioning to him earlier, uh, one of our chaplains had a heart attack last year.	Loss of multiple close friends
Me personally, in the last couple of years, I’ve had so many deaths. My, my immediate family has died out. I’m the only person left. Um, I lost both my parents and my only child. And so, for me, I’m not, I don’t know whether I’m, I can’t say that I’m still not *in* bereavement.	Loss of multiple family members
I've seen so many people pass. And at one time I remember I was a resident care coordinator at one of our sister facilities, and when I first got that job I started keeping a little log of my residents and when they passed. And sometimes I'd pull that log out and look at the names and I thought wow you know I just can't believe that all these people have passed away since I've been working here. And it's just a very sobering thought. And it just reminds you every day how precious life is.	Loss of multiple residents
You know, one of the things that I became very aware of having lost a very significant person in my life, father and my child life partner, in the midst of losing several clients simultaneously and within the same year my grandmother. They all died within that same twelve months. The impact personally probably was most felt in trying to figure out how I am supposed to balance all of these things while I continue to go to work and smile.	Loss of family members and residents

In six interviews, staff and chaplains discussed the loss of multiple family members or close friends quickly. One staff member explained that her entire immediate family had died within the past two years. Five interviewees discussed the difficulty of losing multiple residents/patients in a short period of time. For example, a chaplain told us that he had lost 434 client deaths in the past ten years, in addition to family members and friends, and that it becomes "overwhelming." He knew the number immediately, without having to consider it or check any records, which led me to believe that he contemplates it regularly. Another staff member described the loss of nine residents in the winter months, and explained that she and all other department heads have an open door policy so that staff can come in to talk or vent if they feel agitated. Five staff members also discussed the difficulty of suffering professional losses while still grieving their personal losses. Finally, while most staff members described the difficulty of suffering multiple deaths, one staff member also described her personal losses as having the benefit of helping to prepare for work in the field. She stated:

> Well, I've been in this field a long, long time, and I think being in this field prior to him even being sick kind of helped me through his death, and his illness, because I'd grown accustomed to knowing a little bit more about how to accept if something happens at this time, so, it kind of helped, it helped me with my personal issues by working in this field like I do.

Working as a caregiver and experiencing loss in one's personal life may be one of the key factors that leads many individuals to work as professional caregivers.

Domain 3: Grief and Added Stressors

In addition to cumulative loss, I have found numerous other factors that add to the stress of dealing with death. In some cases, eliminating those stressors may ameliorate residents' grief or stress. One such factor, a close relationship with the deceased, can be seen from many of the quotations in the grief section, and thus will not be discussed in depth here. Twelve of the seventeen interviews included a discussion of the difficulty when particularly close residents die.

Family Dynamics

The most common stressor was broadly characterized as family dynamics. Fourteen of the seventeen interviews involve some form of "family dynamics," or situations in which staff members undergo additional stress due to their interactions with family members, especially due to family strife. These included cases in which family members are hostile towards staff or towards each other. A more detailed description can be found in Appendix A.

Family Dynamics	
"Oh, y'all did this. Y'all did that!" you know, the combative kind. When I run across those kind of people, I generally direct them to someone that's higher, like [the administrator], someone that can smooth the situation. 'Cause sometimes they'll come at us so aggressive.	Anger directed at staff
[A family member's] mother had died, and he was sitting right outside the unit, but he was looking really troubled, really angry, typical grief. And I asked him, 'hey, how are you, what's going on?' And he told me that his mom had just died in here because, he thought it was because, you know, the nurse had took a smoke break. And he felt that he needed to go in there and just shoot everybody in there. Just being honest with you. And I said, 'oh,' then the security guard came up, and he started talking to him, and he went ahead and left. And, he left, I mean, he was gone…So, I saw him months later…I don't think he felt any different about it. What bothered me the most that that nurse, I know those nurses in that unit, had been taking care of her, doing everything they could, but because the one time he asked for her, she was out smoking.	Threatening comments by family
[T]hey're fighting, and everybody's entire care team usually is trying to please, and trying to please [one family member] when she's here, please [another member] when she's here, and Mama, Mama is really sick, you know, Mama, but I feel like sometimes that comes as a shock to them because there are the dynamics…and that's not everyone of course…but I will say, family dynamics will play a tremendous role in the way the death is handled.	Family in-fighting
[W]e had a family member who, um, there were some family dynamics between the siblings. There were three siblings, two of 'em were here visiting the mother. The mother was actively dying and had been for a couple of days. One of the siblings had been to the facility during the day, but she would leave whenever the other two would come. So, she had been here that morning and was here most of the day, but she knew that the others would be here during the afternoon and early evening, so she made a point to leave before they came. Well, they were here that afternoon when their mother passed away, so, of course, one of our nurses called the other daughter to inform her. That daughter was so angry that she came up here and met with the administrator, with the director or nursing, as well as that particular RN who is the resident assessment nurse, because she was angry that she called her and told her her mama had passed away, and nobody told her her mama was dying. And she was home by herself and "you call me and I'm home by myself and nobody from the nursing home thought enough to come to my house."	Blaming staff for results of family in-fighting

[S]ome family members, and the ones that aggravate me the most that I have to deal with: you came, you signed your mother in, you ain't seen her for 10 years, but when she's getting old and frail and about to die and her body's breaking down and she get a bed sore, now you want to come sue everybody…For 30 years she's been fine. Now, she's malnourished; she don't eat. She's, you know, she's declining. Her body's shutting down. Now you want to come and be Captain Save It All. You want to come in now, like you've been here forever and you the upstanding daughter who loves her mama and, and "I want you to make sure that-." You know, if we ain't did her wrong in 30 years, because now she's 92 and dying, we can't make her stay here longer for you to get your guilt right. And that's another thing we have to deal with: family guilt. And that's another thing what we have to even [sigh] with death and dying and all that coming, now this play into it, a lot of guilt for families come out at that time. *Lot* of family guilt coming out. And they strike out at you, because they are mad at themselves.	Family anger associated with guilt
[T]he extended family is now going to the house, just picking up things out of the house… But I, I truly do see quite a difference, but I almost wanted to say, sometimes it is the hurtful thing, it's all about the money.	Family concern with assets
These people have money, when they come in here, and they want this, this, this, and this for Mom and Dad, you're supposed to jump, and you're supposed to say how high and how many times you want to jump…The complaints. Why didn't y'all call us and tell us that his pants were too big, too small, because of the edema. Well, we did call you. We called you several times. I mean, Walmart is right up the road. Why don't you go and get him some pants? We go down there sometimes to get him dressed for bed or dressed for the morning and you couldn't even find a pair of pants to put on. And this guy had money. Money, money, money. He was very wealthy. There's no reason for that. That's frustrating to me.	Unhelpful family members
The biggest challenge for us, I think, is the families. I think a lot of our families are in denial about what may be going on with their family members when they're declining. So, for me, for me and the other nurses, I think it's not so much the resident as the family that creates the challenge.	Family members in denial
So they'll rely on their, their parent, or they'll rely on the, the aunt or the uncle. Usually it's the aunt. Usually the aunts I've seen are the most powerful in the group. Aunts would say "we want everything done." Even though the child may say "I don't want everything done. I don't think that's what they really would want." Spouse is just kind of in a state of loss.	Last minute end of life decisions

Family dynamics can take the form of anger towards staff. Often grief involves anger, and such anger may be taken out on the staff members who cared for a deceased resident. One sympathetic staff member attempted to explain this anger.

> When somebody is dying when your parent is dying or your mother your best friend your husband your wife you cannot control that situation. And there's nothing that you can do but what you can control is everything around them. You can control how the medicine is being given you can control when caregivers come and go what care is being given what care is not being given. And I think a lot of times they will very much try to control that situation because they're powerless to control what's not in our hands. And so

> sometimes that means that they become a little bit dissatisfied. Sometimes it is warranted. Sometimes it's not. You can tell it's coming from an emotional place and that's hard.

Family in-fighting is common, and often it negatively impacts staff. For example, in one case, a family member left because she did not get along with other family members, and then became upset with staff because she was not present when her mother died. Some staff members were particularly frustrated with family members who have not visited or cared for their loved ones.

In some cases, staff are distressed because family members seem primarily concerned with the distribution of possessions of the deceased. In one upscale facility, staff complained about family members who constantly complained and never helped with their family members. Staff can also struggle when families are in denial about their loved one's condition. Finally, multiple staff members discussed family dynamics that emerge when discussing end of life care.

Difficult Behavior from Residents

Difficult Behavior from Residents	
[A] lot of our patients come in first for rehab, and then they transition. If we have, if we see that, a lot of that anger or disappointment or grief might come after you've failed to be able to go home from therapy, you know. And then that's a whole 'nother, a whole 'nother thing. There is anger involved in that, I mean, there's family members telling folks "nope, sorry. You worked hard but you still can't go home."	Staff sympathy with resident anger
I get, the residents, I can deal with them, because I know that can't help it. And you got some that's alert and that try to test you. But you find your way to deal with them. Yeah, I got one over there. He'll come out and cuss me out every time. And I said "and I still love you"… And I've been called some stuff. Ooh, I've been slapped, hit, kicked, bit, spit on…. I've been in this twenty-some years, so I have met, I had some residents way back when where I wasn't nothing. And they let me know I wasn't nothing. And I still smile. I got slapped so quick I didn't know I was slapped until it started hurting.	Sympathy with violent behavior from residents
The thing you have to, key thing is observing. We had one patient here and they took – I wasn't doing admissions then –. He was quiet. I mean, deathly quiet. I don't, I don't scare easily. He made me uneasy. And I told them, "y'all got to do something 'bout him"…He's too quiet. You can't talk to him. You, you can't get him to do anything. He's the type that will snap. He's gonna be that impulsive one that you don't see it coming. It just comes"… And that's what happened… [He] just snapped, just beating up everybody.	Dangerous residents

In six interviews, staff members described angry, abusive, or difficult behavior from residents. In some cases, staff believed that this resulted from frustration due to their declining condition. Staff members generally understand and sympathize, even in the most severe cases where residents have become abusive. At a facility that works with residents with behavioral issues, a staff member described the need for careful screening of residents to avoid taking someone that will pose a danger to staff and other residents. She also talked about the need to closely observe any residents with concerning behavior patterns. In less severe cases, it can be helpful to identify the root cause of the anger and express empathy and understanding. One staff member explained that anger is a natural and often justified emotion.

Frustration with Rules and Excessive Paperwork

In seven interviews, staff members discussed how rules and excessive paperwork make their lives difficult. One staff member discussed how difficult it is to keep certain residents from hurting themselves without using anything that could be characterized as a restraint, even if it is merely designed to prevent the resident from falling out of a bed or chair. She also explained that it takes her two hours just to go through the 88-page admission packet for each resident. She stated that, “[n]ursing homes are always walking on eggshells, trying to take care of the patient, trying to satisfy the family, and trying to make sure that we’re within legal guidelines.” In handling documentation of end of life wishes, she was unfamiliar with a POLST or Advance Directive, and instead had multiple forms that she used. She frequently repeated her desire to consolidate paperwork to a single sheet of paper.

Another admissions director spoke at length about his frustration with private insurance policies and the struggle helping individuals who did not qualify for Medicaid. His facility included many younger people who sustained serious accidents or illnesses but had not yet spent down all of their money, or that had spouses who still had resources. He also expressed a great deal of frustration with the Medicaid system, and having to go through bank statements to see if individuals and their spouses had spent down enough resources to qualify. Finally, he also discussed the fact that long-term care is a highly regulated industry, and all of the new rules that are coming out make his life much more complicated.

A third admissions director discussed the process of having to call in a coroner when one of their short-stay patients died. She described it as “quite an ordeal” for everyone. She also described frustration with the Medicare/Medicaid payment system. In less severe cases, sometimes Medicaid would recommend that residents be placed on “a lower level of care,” but there might not be any provider available that can provide the lower level of care. On the other hand, if a severely ill resident decides to go on hospice, Medicaid no longer pays the facility directly. Instead it paid the hospice service, which in turn pays some of those funds to the LTC facility, creating “another layer of reimbursement,” despite the fact that they continued to provide the same level of care. She explained that they are responsible for ensuring that all of their residents are comfortable, regardless of whether they are on hospice. Another staff member explained that they are capable of and continue to provide all of the same medical services as hospice. To her, the most helpful hospice staff member was the chaplain.

An administrator described the difficulty in using a POLST with residents that had to be sent to the hospital. She explained that hospitals frequently did not use them, and that the form did not often make it back. She would have like to see POLST preferences (and other electronic health records) transferred in the same manner as Medicaid records. She also bemoaned the added requirements associated with the Minimum Data Set records, stating that it diminishes time that can be spent with residents.

Self-Care

In five interviews, staff discussed the lack of self-care within the caregiver community. As one staff member explained, “it’s important to realize that in order to care for the people around you, you have to take care of yourself…Often we as therapists and helpers do not seek help. We are kind of the worse to go and ask for help.” Multiple staff members discussed the importance of taking time away from work. One explained that staff should take 2-3 vacations per year to get away, and one regular day’s off, it is important to totally disconnect from the work to give oneself a true break.

Other Added Stressors

Several other added stressors were discussed. Three staff members were frustrated by requests around the administration of morphine. Sometimes, staff expressed frustration that family members were pressuring them either (1) to give too much morphine to residents, which led them to feel like they were shortening the residents’ lives, or (2) insufficient morphine to provide comfort. Other staff talked about the failure to provide advance notice to staff if a resident under their care dies while they are off duty. Discovering an empty bed is not the best way to find out that someone they cared for has died. Three staff members talked about not knowing how to handle seeing a dead body for the first time (2) or not knowing how to talk with grieving family members (1). They suggested that extra training would be helpful.

Part 2: Case-Based Results: Grief and Cumulative Loss

This section gives an in-depth description grief experienced by five individuals due to their cumulative losses. In three cases, one of the losses was a child or life partner. Those three staff members described themselves as being burned out, suffering a nervous breakdown, having to leave work for three months due to an inability to function, and/or experiencing physical grief symptoms. All three dwelled upon the deaths for years. The other two bereaved staff members described in this section suffered from the cumulative loss of multiple clients/residents. One described himself as being burned out and looking for a change. The other showed signs of burnout and spoke extensively about his empathy with grieving families. All five interviews included descriptions of crying and other emotional symptoms. In addition, all five staff members talked about self-care, describing their personal self-care and/or the general lack of self-care within the industry.

Case 1

One interviewee had lost both of her parents and her only child "in the last couple of years." She reported that her physician pulled her out of work for three months, and that she was literally pulling hair out of the back of her head without being aware of it. At the time of the interview, she described herself as still in bereavement, and she explained that it had taken her months to even become functional and able to work. Later in the interview, she discussed the loss of a resident who had been extremely close to her, stating that after that loss, she had never allowed herself to become that attached to a resident again. She also discussed the inability to cry after that death, stating that if she had cried, she probably would have felt better.

This staff member talked at length about the support system within her facility that enabled her to come back. In particular, she spoke about the administrator in her facility. When he heard about the loss of her child, he dropped everything and drove straight to her house. He ensured that she was taken care of at all times by him or additional staff, who performed simple tasks like picking up her medicine and ensuring that she received mental healthcare. He served as a pallbearer at her son's funeral and allowed her to take off as much time as she needed. She took off three months, and then came back on a part-time basis, working no more than four hours per day in the beginning. The familial environment and support that she received from within the facility were crucial. When we spoke to her, she was still in bereavement, but she was able to function and talk about her grief.

Case 2

Another staff member explained that her son, father, stepfather, and baby brother all died around the same time. She stated that she "got burned out" and "had a nervous breakdown." Like the previous staff member, she could not function after the deaths. After she took some time off, she was offered a position in Environmental Services, which she viewed as less stressful than her previous work as a CNA and which enabled her to spend more time chatting with residents.

Like the previous staff member, she also described forming close relationships with and grieving over residents. One resident that had formed a particularly close relationship was the mother of one of her coworkers. They had formed a truly familial relationship: the resident referred to the staff member as her "other daughter," saying "she's just lighter skinned, but she's mine." The staff member further explained that this resident had been like an aunt to her son, and that when the resident died, she could barely breathe, and she cried as much as her coworker (the biological daughter). The staff member also described missing the daily greetings from other residents who had died. She compared this emotion to the one she feels when she thinks about discussing something with her deceased mother, only to remember that her mother has died. To her, both family and resident losses can be devastating, but she placed great value on these relationships and the support offered at the facility, which helped her to recover after the deaths.

Case 3

We also interviewed a therapist working in LTC who lost her life partner (the father of her young daughter), her grandmother, and several residents with whom she had a close relationship during the span of one year. We interviewed her twice, and she broke down into tears during both interviews. She reported extensive physical symptoms of grief, including pain in the knuckles, pain in the neck, migraines, digestive issues, and greater susceptibility to viruses. She described physical and emotional symptoms of grief as having a compounding effect upon each other. She explained that three years had passed since these losses, but she still struggled with them. She described grief as something that can take a hold of her and consume her, so that she does not even know what date or time it was. She also discussed the added stress of having to walk a small child through grief while she was still grieving. To her, grief is a journey, and she expected to still be on that journey for many years.

This staff member talked at length about the importance of caring for oneself in order to be a good caregiver to others. She explained that few professional caregivers take the time for self-care and few LTC communities support it. Self-care can take numerous forms. It may involve setting aside time to sit alone and relax and caring for one's physical health by eating well. She also benefited from a life coach and from a health care community called "Resilience over Burnout." In addition, she was able to go to a grief training that dealt with using music to deal with grief, which provided both personal and professional benefits to her.

Finally, her support network is crucial to her. It includes several of her coworkers as well as online community, where she was able to pose specific questions and benefit from the experiences and insights of others. She explained that LTC facilities should offer multiple support options, and staff should take advantage of them. To her, it is important for a facility to make professional therapy services available to staff. By investing resources in staff well-being, facilities are showing staff that their well-being matters. It is important that facility leaders show empathy for staff, and she wondered if some of them might benefit from training in this area.

Case 4

We also conducted a group interview with three chaplains that work in LTC facilities. The chaplains extensively described burnout, not only in themselves but within the industry more broadly. One chaplain talked at length about the impact of cumulative loss. He explained that the 434 client deaths that he had experienced in the last ten years “consumed” him, leaving him burned out and looking for a change. Like the previous staff member, he spoke extensively about the need for self-care and how people within his profession “don’t know how to ask for help.” He talked about the need to create boundaries for himself. When he feels overwhelmed by client problems, he steps back to consider whether his stress has more to do with his own issues than those of his clients. He described extreme fatigue, and repeatedly discussed the importance of creating some separation from his clients, accepting that he cannot fix everybody, and taking some time for himself. Finally, he also discussed the importance of rituals to memorialize the deceased.

Case 5

The final staff member works at a facility that has 3-5 resident deaths every month. His interview was conducted at the end of the winter, and he went on to state that during the winter months, they lost people that they were not expecting to lose. He talked about dwelling on one particular resident, whose death was totally unexpected and who had no family. He also frequently showed empathy for the family members. This is particularly true when he sees young residents on ventilators, who do not react to any stimulus. He does not believe that they should be kept permanently in that state, with little quality of life, but he acknowledges that if he were the parent, he cannot say for certain what he would do. He seemed to put himself in their place, imagining how he would react if the suffering resident were his own child.

He similarly empathizes with family members trying to make financial decisions and handle bureaucracy in the midst of a devastating catastrophe. In one case, while talking to a 55-year old man trying to figure out his wife's care, he imagined what his situation would be at the age of 55, the amount of assets, and the process of spending them down in the event of a catastrophic accident of a family member. Throughout the interview, he expressed frustration with the Medicare/Medicaid system, as well as other regulations and bureaucratic paperwork. He expressed frustration with his employer, stating that "this company has just drove me over the edge sometimes. There's so many things that I'm burdened with." At home, he does not want to talk about or think about his work: he just wants to put it out of his mind.

Finally, he discussed the suffering of residents on a ventilator. He has "heard them gasp like there is no tomorrow." He explained that the ventilator is helping them breathe, but they are fighting it, trying to breathe on their own.

When asked what keeps him in this job, the admissions director described the rare success stories. He described one resident who they had been able to remove from a ventilator and discharge home. He stated that "those are the rare moments, and it makes me happy saying that we are able to let someone home after a catastrophic event." He also described a resident who had been discharged in a wheelchair and had come back to visit several months later fully able to walk, without even the need for a walker. He ended the story by stating "I felt happy…[L]ately, I've not been finding those moments." Towards the end of the interview, he stated, "I don't know. I really, to be honest with you, this job, I have…they have not been able to keep someone in the post for a very long time…this…used to have been a fun job….I don't know, maybe you got me in a question mark mode." Despite all of the pressure and stress from the demands of the job, this admissions director had managed to find satisfaction, or feel a sense of personal accomplishment, in this job previously. At the time this interview was conducted, he seemed to have lost that feeling.

Unlike staff at some of the other facilities, this admissions director did not feel that there was a home-like environment within his facility. He described the manner in which bodies were removed: after residents are shut in their rooms, staff noisily wheel the body down the hallway, banging the door as they exit. He commented that it is a person who passed away, and this is people's home, and he doesn't understand why a home is run in this manner.

DISCUSSION

Several common threads arose during the interviews. Throughout most of the interviews, staff discussed the relationships that they formed with residents. They place great value on these relationships, which bring happiness to themselves and their residents, but they suffer when residents die. Interviewees discusses emotional symptoms of grief in every interview and crying in almost every interview. Staff also express great empathy for the families, oftentimes literally feeling their pain. Images of grieving family members sometimes bring staff to tears or remain ingrained in their memories for an extended period. In some cases, seeing family members grieve reminds staff of their own, prior grieving experiences.

All staff members that were interviewed have suffered multiple losses, and most have suffered cumulative loss. All staff members that suffered cumulative loss described at least four categories of grief symptoms (see Appendix for categories), and in every case, crying was one of those symptoms.

A familial, supportive environment within the facility often helps to mitigate the impact of grief. In cases 1 and 2, the interviewees suffered extensive grief due to close relationships with numerous individuals that died, both inside and outside of the facility; however, the interviewees also spoke extensively about the benefits they received from the familial, supportive environment within the facility. The presence of this familial environment is prioritized at every level of leadership. In a separate interview, the administrator of that facility explained that he will not be remembered for how well he completed paperwork, but for the type of support that he gave to staff members such as the interviewee in Case 1. The interviewees in Case 1 and Case 2 were each able to take time off and receive various other forms of support when they needed it. It is clear from the transcripts that, despite the pain that they have suffered, they love their work and their facility. In addition, their facility has been able to maintain a five-star overall rating and a five-star rating for quality metrics on the CMS Nursing Home Compare website, despite below average staffing levels and limited funding from Medicaid for many of their residents. Even with limited staffing numbers, staff have pulled together to provide outstanding care.

In Cases 3-5, staff members did not describe the same familial environment. The staff member in Case 3 mentioned that her support network included coworkers, but she largely had to go outside of the facility to find her support. Although she worked as a therapist, she was paid to work with residents, not staff. This interviewee left her facility within one year of this interview. In Case 4, the interviewees were chaplains, whose work was not limited to one facility, and they did not describe a strong support network. In Case 5, the interviewee was an admissions director in a facility, but he did not receive any grief support from his facility. We have not kept in touch with the interviewees in Cases 4 and 5, but both expressed doubts about continuing in their current line of work, either explicitly or implicitly. The facilities in Cases 4 and 5 also have low nursing home compare ratings (two-star and one-star respectively).

A familial environment pertains to all stakeholders within the LTC facility, including the families. As noted in the results section, family dynamics are a stressor described in most of the interviews; however, it is more prevalent in some interviews than others. In Cases 1 and 2, the interviewees each reference only a single case where family dynamics are a problem. By contrast, in Cases 4 and 5, difficult family dynamics are described six times and four times respectively. As shown in the first section of the results, some staff members describe family dynamics as the most difficult part of their job. Those that reported a familial environment generally described it as something that only occasionally comes up.

Another common added stressor related to being overburdened with paperwork and regulations. In two facilities, the admissions directors spoke at length about the many hours that this takes. One admissions director talked about the many pages of redundant forms that she had, and another talked about the burdensome struggle of trying to help families navigate bureaucracy. However, staff members who reported a supportive environment did not describe being overburdened with paperwork. In the long run, facilities will benefit from investing in the well-being of their workforce reducing stress as much as possible. By working to streamline paperwork, simplify regulations, and provide additional assistance to staff where needed, facilities can benefit from a healthier, more productive workforce.

As noted in the results section, personal accomplishment is one scale on the Maslach Burnout Inventory. Other studies have found that low levels of personal accomplishment are associated with high levels of burnout.[14,34] In this study, six staff members reported being comforted by feelings of satisfaction or personal accomplishment in their work. As noted above, the staff member in Case 5 described successful outcomes in residents as a factor that had helped him to enjoy his job. Unfortunately, he noted that such success stories had not occurred recently, and his job is not as enjoyable today as it once was.

Five other interviewees discussed personal accomplishments within the workplace from which they derive satisfaction. None of those staff members described the rarer grief symptoms such as dwelling on death or physical symptoms of grief, and none of them expressed any inclination to change their line of work. Delivering quality care involves dedicating time and resources to each resident. Reducing the workload and stress levels of staff, and allowing them to spend time with their residents, can enable staff to derive more satisfaction and personal accomplishment from their work. This practice will provide benefits to staff and to residents.

Limitations and Potential Biases

As in all qualitative studies, participants cannot be selected randomly. All interviewees were volunteers who were willing to talk to us about their grief experiences. Before beginning our interviews, we informed staff about the topic and gave them the opportunity to decide whether they wanted to participate in an interview. In some cases, leadership suggested candidates that they thought would be comfortable speaking to us.

In selecting the interview transcripts to analyze, I used a process known as "purposive sampling." I selected interviews in which staff gave detailed descriptions of their experiences and recounted personal stories. I also ensured that my selection included staff from a variety of different facilities and from many different positions within the facilities (leadership, nursing, environmental services, etc.).

Despite the efforts to ensure diverse participation, the study may still be susceptible to selection bias. Some staff that suffered from severe grief symptoms may not have wanted to discuss them. Staff that felt less burdened by grief might have believed that they could not contribute to the conversation, and thus they may also have chosen not to participate. Finally, the facilities that chose to invite us to interview their staff might be those facilities that are more proactive in caring for their staff.

This study also has geographic limitations. All facilities were located in southern Georgia; however, the facilities were otherwise very diverse. I selected some interviews conducted in facilities located in a city with more than one hundred thousand people and other interviews conducted at facilities in a town with fewer than five thousand people. Nursing Home Compare rates all facilities, giving them between one star and five stars, and this study includes both one-star and five-star facilities (and facilities with ratings in between). The size of participating facilities also varied greatly, from 85 certified beds to 228 certified beds. Finally, the type of patients served varied greatly. For example, while most facilities had many residents who were eligible for Medicaid, there was one facility that refused to accept Medicaid, catering to a higher income population. Participating facilities also included one facility that had residents on ventilators and one that catered to residents with behavioral issues. To protect the privacy of our interviewees, we did not collect demographic data from them.

This qualitative study uses cross-sectional data: the interviews were taken at a single point in time. Thus, causal relationships cannot be positively established. To the greatest degree possible, I have eliminated bias from within the coding process. I have studied LTC grief for four years, and I had naturally drawn some conclusions before beginning this analysis. However, I created objective, written criteria for the application of each code within the interview. In addition, I had a second coder, with no prior experience in this field, double code my interviews to verify my objectivity. These are best practices in qualitative analysis.

CONCLUSION

LTC staff develop relationships with residents, and grief from their deaths is inevitable. This grief is commonly manifested through crying, burnout, empathy with grieving families, and a variety of emotional symptoms. In some cases, staff also dwell on the deaths or experience physical symptoms. These symptoms are often compounded by the cumulative loss of close friends and family members and/or multiple residents within a short period of time. In order to mitigate the symptoms of grief, LTC facilities should work to develop a familial, supportive environment for all members of the LTC community. They should prioritize the health and well-being of their workforce and offer as much support and as many resources as possible to help manage grief. Finally, they should ensure that staff have enough time with their residents and support from their coworkers to build relationships with their residents and provide quality care in which they can take pride. A feeling of personal accomplishment in one's work can mitigate the impact of grief.

CHAPTER 4

DO FAILURES IN END OF LIFE PLANNING EXACERBATE THE PAIN OF THE BEREAVED? AN EXAMINATION OF THE IMPACT OF THESE FAILURES AND THE TOOLS THAT CAN PREVENT THEM[3]

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[3] Brown-Brundage, A.A., Skelly, C., Clack, L., O'Rourke, P., Miles, T.P. To be submitted to the *Elder Law Journal*.

ABSTRACT

Research Purpose: This paper examines the impact that failures in end of life planning have on the grief experiences of caregivers and family members. These failures may result from a failure to discuss end of life wishes, a failure to document those wishes, or a failure of medical professionals to follow the documented wishes of their patients. It also examines best practices in end of life planning.

Methods: This paper adopts a novel type of mixed methods analysis by combining legal analysis with qualitative analysis. The legal analysis examines successful cases in which families sue medical providers for the pain that they experienced due to the medical providers failures to honor the documented, end of life wishes of their loved ones. This legal analysis is combined with a qualitative content analysis of seventeen interview with long-term care (LTC) staff and the hospice chaplains that work with them.

Results: Caregivers and family members suffer substantially when a patient's end of life wishes are not carried out. This is true both when patients fail to document their end of life wishes and when they successfully document those wishes but medical practitioners do not follow their wishes. When medical providers fail to honor documented end of life wishes, family members are often able to recover substantial financial settlements to compensate them for this pain. Physician Orders for Life Sustaining Treatment (POLST) is an effective tool to promote end of life planning, and when discussing the subject, LTC staff should talk about death as a natural process and focus on alleviating pain.

Conclusion: LTC facilities and hospitals should adopt formal policies to promote end of life planning both to mitigate the grief suffered by staff and family members and to reduce their own liability.

INTRODUCTION

Individuals have the right to decline painful treatments at the end of their lives. Unfortunately, in many instances, a patient's wishes with regard to life-sustaining treatment are not followed due to (1) a failure to discuss those wishes; (2) a failure to document those wishes; or (3) a failure of medical personnel to carry out their documented end of life wishes. The harm that can come to a dying person when those wishes are not carried out is self-evident to those who have cared for the dying. They can suffer a long, drawn out painful death. Multiple plaintiffs have won million-dollar legal settlements for suffering resulting from unwanted end of life treatment.[49,50] However, this manuscript focuses on the less frequently discussed pain of family members and professional caregivers. In the legal context, this is referred to as bystander pain or bystander damages.

To examine this bystander pain, I look to two sources. First, I analyze court cases, where family members of a deceased relative have successfully sued for damages that they suffered due to medical providers' failure to carry out the documented end of life care instructions. I chose to focus on cases where the family members sued not only for the pain suffered by the decedents but also based upon their own personal pain. This bystander pain is traditionally very difficult to establish in a court of law. However, in the cases below, courts have found that plaintiffs have produced sufficient evidence of this pain to bring the case to a jury. In most of these cases, I have located media coverage indicating that the defendants agreed to pay out of court settlements to avoid a potentially costly jury trial.

The second part of the analysis utilizes qualitative data from interviews that occurred in the long-term care setting. As part of a CMS-funded project, I worked with the University of Georgia team to conduct interviews of LTC staff. I have carefully analyzed seventeen of those interviews, specifically focusing on discussions by LTC staff of end of life planning. In doing so, I gained insight into benefits of end of life planning not only to the dying, but also to family members and to the staff. I also learned about best practices related to discussions of end of life planning with family members. I have analyzed the relevant sections of the interviews and laid out the results below.

BACKGROUND

POLST: A Tool to Facilitate End of Life Planning

One tool discussed by LTC staff for end of life planning is a document known as the Physician Orders for Life-Sustaining Treatment (POLST). A version of this document is used or is being developed in all fifty states (other names for it include POST, MOLST, and MOST). The Georgia POLST is a one-page medical order, signed by the physician and the patient, which lays out a patient's end of life planning preferences. It contains check boxes which indicate whether the patient would like resuscitation, ventilation, artificial feeding/fluids, and/or antibiotics. It also contains space where physicians can write in additional comments if needed. Most states have legislation in place that provides legal immunity to medical providers who follow them. In Georgia, the POLST is relatively new. It was developed in 2012, but the first POLST legislation was not enacted until 2015.[51]

RESEARCH QUESTIONS

1. When end of life planning is not successfully carried out, either because end of life wishes are not documented or because medical professionals do not carry out those wishes, what is the impact upon family members and caregivers of the deceased?
2. Does the Physician Orders for Life-Sustaining Treatment (POLST) form effectively promote or facilitate successful end of life planning?

3. What other techniques facilitate the promotion of end of life planning?

RESEARCH PURPOSES

The first purpose of this manuscript is to examine the impact of end of life planning (or the lack of end of life planning) on family members, caregivers, and other close friends of the deceased. When talking about end of life planning, both in the legal and public health settings, most people focus on the dying individual; however, it is their loved ones who will remember the manner of their death for years to come. Were the wishes of the deceased understood and followed? Did they spend their last moments in extreme pain? The second purpose of this manuscript is to examine the tools that can help facilitate or promote the discussion, documentation, and adherence to a resident's end of life wishes. This manuscript examines use of the POLST and other best practices described by LTC staff.

METHODS

This mixed methods approach includes a unique combination of legal and qualitative analysis.

Part 1: Legal Research

The first step was to search for evidence of legally recognized and legally compensable emotional pain on behalf of "bystanders" (family members) that arose from a failure to follow documented end of life wishes. To date, there have been numerous claims brought against medical providers for failure to follow end of life wishes. Most are brought on behalf of the estate of the decedent, for damages suffered by the decedent before death; however, sometimes family members bring claims on their own behalf for their own damages created by witnessing the suffering and death.

Through a combination of legal database and secondary source research, I compiled a list of cases that potentially related to end of life planning. In addition to identifying each relevant case, I had to ensure that the cases remain “good law.” Sometimes a case can be overturned, either by a subsequent court ruling or by a statute. These cases may still be useful in certain contexts, since often, cases make rulings related to more than one legal issue, and the overturning of one finding does not necessarily invalidate the other findings. However, during legal research, attorneys must ensure that they are not citing a ruling that has been overturned.

In addition, attorneys must search to see if there has been any other “negative treatment.” Sometimes, a subsequent case can cast doubt upon the rationale of the earlier case and limit the scope of its findings, without technically overturning it. This would be classified as “negative treatment.” This reluctance to completely overturn a case often stems from a principle known as *stare decisis* (the principle that precedents should be followed in subsequent cases). When a ruling in a case receives negative treatment, one may still discuss that ruling, but one should also talk about any limitations on it that result from the subsequent negative treatment.

After compiling the list of cases, I analyzed each case to determine (1) whether it included claims for bystander damages, and (2) if yes, the nature of those damages. In this context, bystander damages are damages to a person who witnesses the pain of the decedent. To my knowledge, nobody has ever published an analysis of these cases that focused on these bystander damages. I carefully read through all factual and legal issues presented in each case in order to provide a short synopsis of the factual background and the legal findings related to the claims for bystander damages.

In most of the presented cases, the defendants had filed a motion to dismiss the legal claim. In the field of law, if, in the opinion of the court, the plaintiff has not pled sufficient facts to establish a case for damages, the court can dismiss the case. The court will not determine whether the facts pled by the plaintiff are true: that determination is left for the jury. Instead, it will inquire whether, assuming the plaintiff's facts are true, a legally sufficient case be made against the defendant. If so, the case can proceed to a jury trial. Often, at this point, defendants will attempt to reach a settlement with the plaintiff to avoid a potentially costly trial, a potentially large jury verdict, and a public, legal finding of liability. In each case in which a defendant's motion to dismiss was denied, I searched through media outlets to locate evidence of a financial settlement.

Part 2: Qualitative Research

For Part 2, I analyzed qualitative interview data collected from staff that work in long-term care (LTC) to find evidence of their experiences with end of life planning. These interviews were conducted as part of a CMS-funded quality improvement project, approved by the University of Georgia Institutional Review Board.

Because I am analyzing previously obtained interview data, I selected qualitative content analysis (QCA) as the best method for the analysis.[38] The first step in the QCA process was to create a coding frame. My coding frame initially included five domains; however, only two domains are relevant to these research questions. The first relevant domain is "End of Life Planning." Here, I noted staff discussion related to end of life planning, including opinions about its benefits and inherent difficulties. I also used data collected in a domain entitled "Best Practices," which documents best practices discussed by LTC staff. Two of those best practices relate specifically to the promotion of end of life planning, so I used data that fell under one of two codes: "POLST promotion" and "end of life comfort or emphasis of death as a natural process." A full copy of my codebook, which defines all categories and codes, is included in the Appendix.

After defining the codes, I conducted a process called "pilot coding," whereby I tested out my codes on three interviews. The first step in this process involved segmentation, whereby I carefully read through interviews and selected the relevant sections for analysis. Next came the actual coding, whereby I highlighted bits of text that fit within a code in the domain, and I entered them onto a Spreadsheet. All interviews were double coded by a second coder to ensure objectivity and consistency of coding. Once the pilot coding was completed, and all necessary changes were made to the codebook, I coded the remaining fourteen interviews. These were also double coded by a second coder to ensure objectivity and consistency in coding. Because I have a relatively limited amount of data for these questions, I adopted the "continuous text" method of reporting results related to end of life care. However, I included a text matrix to show POLST usage, due to the extensive data collected in that category. Continuous text and text matrices are alternative methods of presenting QCA data.[38]

RESULTS

Legal Research Results

Damages Claimed by Family Members based on their own Suffering

One of the earliest cases in which such damages were brought was the 1998 case in Illinois: Gragg v. Calandra (*Gragg*).[52] In *Gragg*, the Plaintiff, Geraldine Gragg, was the daughter of Florian Gragg and Ann Gragg. The damages arose from Florian Gragg's hospitalization; however, before this case was brought, Ann Gragg died. Geraldine brought claims both for her own personal damages and for the damages suffered by her mother as a result of her father's treatment at the hospital. This case is unusual in that no claims were brought on behalf of the patient himself (the father). In other words, all complaints in this case stem from damage suffered by the family members (bystanders). The initial trial court dismissed her complaints, but that decision was reversed in part. The Appellate Court found that Geraldine could proceed (to a jury trial) with a case for financial damages (the cost of the treatment) on behalf of her mother's estate, and with cases for intentional infliction of emotional distress both on her own behalf and on her mother's behalf. This means that, as a matter of law, there are sufficient facts alleged for a finding of liability. These claims could proceed both against the doctors who operated on them and against the hospital. The court found that even though the doctors were independent contractors, the hospital can still be held vicariously liable under the doctrine of apparent authority. Given the manner in which the hospital advertises, it would be reasonable for a lay person to assume that the hospital had some degree of control or authority over the staff.[52]

The claims most relevant for this analysis are the claims of intentional infliction of emotional distress. To establish a claim for intentional infliction of emotional distress, one must prove that (1) Defendant's conduct was "extreme and outrageous;" (2) Defendant "acted with the intent or knowledge that there was at least a high probability that his or her conduct would inflict severe emotional distress and with reckless disregard of that probability;" and (3) that the Plaintiff experienced severe emotional distress.[52] For conduct to be "extreme and outrageous, it must be "so extreme as to go beyond the bounds of decency" and "regarded as intolerable in a civilized community."[53] "Insults, threats, and indignities" are insufficient to meet this standard.[53] If the court decides that the conduct is insufficiently outrageous or the emotional distress is insufficiently severe, the complaint will be dismissed or Defendant will be granted summary judgment. If this happens, the plaintiff will never have the opportunity to bring the case before a jury. For example, in Weston v. Advocate Christ Medical Center (*Weston*), a woman sued a medical center and the attending physician because the physician erroneously told her that her sister had a DNR, when in fact her sister did not have a Do not Resuscitate Order (DNR). For this reason, she did not insist on resuscitation when her sister coded. There, the court noted that the plaintiff had never undergone medical treatment for the distress, and deemed it insufficiently severe.[54]

In *Gragg*, the hospital physicians were alleged to have committed several acts that they knew would cause the Plaintiff emotional distress, including (1) verbally insulting Plaintiff for her decision to end life support; (2) refusing to honor the living will and her requests to end life support; and (3) refusing to perform an EEG test, knowing that it would show no brain activity. The court found sufficient evidence of emotional distress for the claim to be brought to a jury.[52] In doing so, the Court acknowledged that, based upon the facts alleged, the plaintiffs have a legal right to proceed with a claim for emotional distress.

In Norris v. Richardson (*Norris*),[55] the decedent's children, James Jordan and Amanda Norris (siblings) brought a suit against their mother's hospital and LTC facility both on behalf of the mother and on behalf of themselves. In October 2014, Sally Jordan (mother of James Jordan and Amanda Norris) signed an advance directive for care, in which she clearly stated that, in the event that she was diagnosed with a terminal illness, she only wanted comfort care. She also listed James Jordan as her health care agent and Amanda Norris as her alternate health care agent. In April 2015, her condition declined, and she was taken to the hospital. She subsequently had to be transferred to a skilled nursing facility for care. Ms. Norris ensured that both facilities had her mother's advance directives; however, the attending physician at the skilled nursing facility nevertheless signed an order indicating that Ms. Jordan was a "full code." Three days later, when Ms. Jordan's condition worsened, she was resuscitated at the facility, intubated by

EMS, transported to the hospital, and placed on a ventilator once inside the hospital. Later that day, facility staff informed Ms. Norris that Ms. Jordan had been transferred to a hospital, although they were not sure which one. Ms. Norris and Mr. Jordan were able to locate her by calling different hospitals.[55]

Upon arrival at the hospital, Ms. Norris informed the hospital of her mother's advance directive. The intubation and ventilation had been done in violation of their mother's clearly expressed wishes. Ms. Norris and Mr. Jordan were then forced to make a decision as to whether to remove the life-sustaining tubes from their mother, thereby ending her life. The physician stated that "it was cruel to make [Ms. Jordan] work so hard to breathe." This was the day before Ms. Norris's daughter's birthday, and she requested time to make the decision, but the physician urged the children to decide within 24 hours. The siblings found this decision, and the urgent nature of it, to be extremely difficult and stressful. They could not bring themselves to make the decision to immediately remove the tubes. During her time there, Ms. Jordan became conscious, and, by pointing to letters, spelled out the question "who placed this tube?" Upon being told that her directive had not been followed, her reaction was "extremely pained and frustrated."

On May 6, an x-ray showed a collapsed lung, and physicians told Ms. Norris and Mr. Jordan that removal of the tubes would cause their mother extreme pain and possibly death. Physicians suctioned the lung and tried to remove the tube, but the procedure failed. The procedure was attempted again on May 7, and it failed. On May 8, it was successful. Ms. Jordan was placed in a bi-level positive airway machine, which was replaced with a nasal oxygen tube. On May 13, at 11:00 PM, Ms. Norris and Mr. Jordan left the hospital to sleep, and at 1:00 AM they were called back into the hospital due to an erroneous belief by staff that their mother was about to die. The same thing happened later that day, at the hospital, when the children had left for lunch. Over the course of that day, Mr. Jordan and Ms. Norris saw a urinary catheter placed in their mother (a treatment that their mother had refused in the past). Their mother was also fed through a feeding tube, and the children watched the medical staff reverse the flow of that feeding tube when her stomach could not process the food. They saw her undigested food dumped by her bedside. Finally, at 5:08 PM, she was pronounced dead.[55]

Mr. Jordan and Ms. Norris brought several charges against the hospital, the LTC facility, and the attending physician at the LTC facility both on behalf of their mother, for her suffering, and on behalf of themselves, for the emotionally painful experience of watching their mother unnecessarily suffer for ten days and for being faced with the difficult decisions relating to the painful processes of removing life support. The charges included medical negligence; failure to train; and *respondeat superior* and alter ego charges (these charges related to holding the hospital and skilled nursing facilities responsible for the actions of their employees and independent contractors). Ms. Norris and Mr. Jordan demanded damages "in excess of $1,000,000."[55] This case was eventually settled out of court for an undisclosed settlement amount.[56] This is not unusual, as sometimes medical providers do not want to publicize large payouts made to avoid liability for wrongdoing. They can therefore make their settlement offer contingent upon a confidentiality agreement.

Norris is not the only case in which a family member claimed that a decision to remove life support was extremely difficult, and damages from life-sustaining treatment could not be mitigated purely by removal. In Doctors Hospital of Augusta v. Alicea (*Alicea*), the daughter of a woman who had been intubated and placed on a ventilator contrary to her mother's wishes could not bring herself to remove the ventilator for another week.[57] As that plaintiff claimed, "letting nature take its course" is different from actively removing life support and ending a life.[58]

However, unlike the plaintiffs in *Norris*, the plaintiffs in *Alicea* did not claim bystander damages: instead they sued only for damages on behalf of the deceased.

Bystanders have also successfully filed claims for medical malpractice committed against their deceased family members, both on behalf of their relatives and individually. For example, in Koerner v. AHS Hospital Corp. (*Koerner*), a New Jersey Court found that a plaintiff could sue a hospital, its physicians, and its nurses for medical malpractice based solely on their failure to follow a DNR/DNI order.[59] The plaintiff was allowed to sue for damages both individually and on behalf of her mother's estate. She claimed that after her mother was resuscitated, she suffered a "diminished quality of life," from intubation against her wishes, daily arthritic pain, end stage lung disease causing breathing difficulties, chest pain, difficulty eating, bowel/bladder issues, depression, dementia, falls, and a stroke. She continued to live for six months after the resuscitation.[59] This case is novel, from a legal perspective, because the court explicitly recognized the right to file a claim for damages directly due to the "prolongation of life," a claim that has been uniformly rejected by many other courts. In other successful cases, plaintiffs and their families have claimed damages due to the resultant pain and suffering, but not directly due to the extension of life.[59] As in many cases, the defendants in this case settled with the plaintiff for an undisclosed sum in order to avoid a finding of culpability and potentially large jury verdict.[60]

Similarly, in Jones v. Ruston (*Jones*), Gwendolyn Jones and Sandra Durbin, daughters of deceased Agnes Liles, filed a suit against their father's hospital for not honoring a DNR.[61] The father survived for an additional two months. In that case, they sued for several damages on behalf of their father, including medical expenses (for post-resuscitation care), physical/mental pain and suffering, loss of enjoyment of life, and cognitive decline. In addition, they sued for “bystander recovery,” which refers to their own damages that arise out of witnessing their father’s pain. Defendants requested dismissal, claiming that pursuant to Louisiana’s Medical Malpractice Act (MMA), they were entitled to have the case reviewed by a medical panel before any litigation began. The Louisiana Court of Appeals found that although the claim brought in the suit was for medical malpractice, the MMA only applies to malpractice as defined in the MMA: any other claim for malpractice would be treated under general tort law. Disregarding a DNR order did not meet the necessary criteria to be covered by the statute. Thus, the case was allowed to proceed.[61] This case likely also settled, but I have been unable to find any media coverage to confirm.

This section presents details of several cases in which civil suits for damages based upon a failure to adhere to a patient’s documented end of life wishes overcame dismissal motions. In *Gragg*, the daughter of a deceased hospital patient sued the hospital on behalf of herself and her mother (the mother had died after the father but before the case was filed). She successfully pled sufficient facts to establish the elements of “intentional infliction of emotional distress.” In *Norris*, the children of a deceased patient successfully filed suit against the hospital and LTC facility where their mother had stayed as well as the medical practitioners that treated her. In the case, they discussed their own pain and suffering due to the failure of the LTC facility and hospital to adhere to their mother’s end of life wishes. In both *Koerner* and *Jones*, plaintiffs were able to successfully file suit against a hospital and several staff members for medical malpractice due to their failure adhere to documented end of life wishes. Finally, in *Alicia*, the daughter of a woman who had been intubated and placed on a ventilator contrary to her wishes successfully obtained a $1,000,000.00 settlement against the hospital and the physician that treated her mother.

Qualitative Research Results

Benefits of End of Life Planning

Three interviewees discussed the benefits of end of life planning, either for their residents or for themselves personally. One staff member explained that avoiding the trauma resulting from witnessing a loved one having his/her chest pumped can be a “tremendous comfort” to families. Another one explained that the hardest part of the death process, for her, is if she must watch a resident suffer before dying. She explained that in those cases, her stress is dissipated when they are able to pass and no longer have to suffer. Another staff member agreed with her, explaining that she used to work in hospice, and to her, if patients have to struggle, it is a relief once they finally die. End of life planning can allow much of that pain to be alleviated, allowing for a calmer, more peaceful death. This benefits the family members, eliminating the stress of watching a loved one in pain.

Staff Pain and Frustration Resulting from a Lack of End of Life Planning

Multiple staff members discussed their frustration with situations arising from a lack of end of life planning. One staff member explained that if a person’s condition rapidly deteriorates, it’s “almost like they don’t have any rights.” Another talked about how awful it is to have patients that are in a terrible condition, constantly coding, but then getting a pulse and being sent to the hospital. He also discussed how terrible it is to see residents on ventilators and dialysis machines at the same time, which is often the result of a “full code.” Another staff member described a resident who was transferred from the hospital in terrible shape and died twelve hours later. She opined that the resident should never have been released from the hospital, and the situation could have been avoided with a POLST.

Staff Stress Due to Uncertainty around a Healthcare Decisionmaker

In some cases, where end of life planning has not been done, it is unclear to staff members who they can talk to for a decision. This may be because nobody wants to step up and make a decision, or it may be because of family strife. In two separate interviews, staff members explained that in those cases, usually the person becomes a “full code.” One staff member explained that generally the family members who want everything done drown out the voices of those who question whether their parent or spouse would really want life-sustaining treatment.

Best Practices in End of Life Planning

Using Physician Orders for End of Life Treatment (POLST) to Facilitate End of Life Planning

At the time that we conducted our interviews, the POLST legislation in Georgia was less than a year old. Some facilities had adopted it, some were in the process of adopting it, and in at least one facility, none of our interviewees had ever heard of it. However, multiple staff members described either (1) how helpful it was in facilitating end of life discussions, or (2) how helpful it would be to use a single sheet of paper for these discussions. Two staff members also suggested potential improvements for the form. These improvements will be discussed in the following paragraphs.

During this project, we interviewed admissions directors in several facilities. Two of them were overwhelmed by the paperwork that they were required to fill out, both with regard to end of life planning and with regard to other elements of the admissions process. One of them described filling out 88 pages of paperwork each time someone was admitted. At least five of those sheets related to end of life decisionmakers. She spoke about how great it would be to consolidate the end of life planning to a single sheet. This admissions director had never heard of the POLST. The other director used the POLST regularly in cases where he thought the family or resident would be open to end of life planning. He saw it as a good tool start the conversation. His main critique was that dialysis did not have its own section on the document. He explained that the default, if nobody wrote any explicit instructions, would be to do dialysis. Dialysis paired with the use of ventilators, he explained, was "a bad combination."

Another staff member explained that she had first heard about the POLST approximately one year earlier. Now, her facility accepts them from hospitals and uses them for new patients who do not have end of life planning documentation in place; however, if a resident already has a DNR in place, they do not ask the resident to fill out the new form. She told us that she likes the POLST, and that you can "do more and tailor more" than some other forms such as the DNR. When asked if there was ever a lack of clarity with regard to the POLST, she noted that the DNR was a bit simpler: if someone had a DNR, it meant that you do not resuscitate, whereas with the POLST, you have to look at what it says.

In one of the more upscale facilities that we visited, use of the POLST was even more widespread. Within the skilled nursing section, staff explained, almost all of the residents had it. In fact, as we went to visit residents, we saw that a copy of the POLST had been left in one resident's room for her to review. This facility was an early adopter, and a staff member spoke positively about the level of detail included on the POLST.

Staff members also described the process of discussing the POLST with residents upon admission. In one case, two staff members explained that in addition to their regular care plan meeting, they schedule a separate advance care planning meeting. The resident and his/her family meet with the social worker and the director or assistant director of nursing, and the social worker brings the POLST to fill out. That staff member explained that more than half of their residents used POLSTs. Other facilities included advance care planning as an item on the agenda at their standard care plan meeting. The physician is not typically present at either meeting, but the forms are brought to him later so that he can review and sign them.

Staff members reported inconsistency in hospital adherence to and knowledge about POLSTs. In some cases, residents came from hospitals or medical centers with POLSTs in place, but this was not the norm. Some staff members complained that hospitals did not use POLSTs or were not trained in them, and one complained that POLSTs sometimes got lost when they were sent to the hospital. She wished that POLSTs formed a part of residents' electronic medical records, so that one could easily look up a resident's end of life planning preferences even if the form was misplaced.

Finally, two admissions directors spoke at great length about the benefits of the POLST. One explained that she really likes the POLST, because it gives residents "a greater say in what they want" compared to the traditional DNR. She also noted that their physician is on board and willing to sign off on resident preferences. She explained that they "piloted the POLST," that most of their residents had them, and that it was nice when they have it completed in advance of any decline in health. That way, they do not to have to fill them out at the last minute while someone is "actively dying." She also explained that she personally derives comfort from having the POLST in place, because it helps her to ensure that the resident is getting the desired level of treatment. She explained "that's really the only way they can continue to speak for themselves." She further clarified, "I want to try to speak for my residents when they can't, you know, speak for themselves. And the, the POLST is a really good way of doing that."

Use of POLST as a Tool to Facilitate End of Life Planning	
If you could get me one sheet, just one sheet, that could explain it all. Cause like I say, you will have family members say "I don't want them jumping on her chest, but I don't want her on machines either.	Consolidation of end of life planning paperwork
We do, we do the POLST here at the facility. Sometimes with a POLST it is, it gets them thinking, because all of a sudden, um, and then they think of the level of cares. And I tell them, "just think about this form. This form is used primarily if they cannot reach you. It is what is the decision. If it's do not resuscitate, then we'll honor that. If it's a full code, we'll do everything like that	Use of POLST to start the planning conversation
If [the resident] is coming from a medical center…they usually have the POLST already. They've done the POLST.	Prior use of POLST
I'm not a hundred percent on this POLST, I'm still learning—but it's like you can add and do more and tailor more than, than maybe some of the other papers.	Positive reflection upon flexibility of POLST
It seems like…when you had a DNR, it was a no-brainer. You had a DNR…[I]f you've got a POLST, you've got to look…"Are they a DNR?" "Okay, well let's calm down, you know, they're DNR."	Learning curve in POLST usage
I know that the POLST is a form that they can get them to fill out. It's kind of a quick form to let them know at the hospital what they want.	Ease of POLST usage
We use POLST in this facility. It starts at admission. During the admission process, we talk to the family about setting up a meeting—which we call an advance care plan meeting...We try very hard to do it within 24 hours of an admission…It's a conversation that at the very minimum the social worker and the nursing staff—usually the director of nursing, sometimes the assistant director of nurses—has with the patient…And then the social worker actually brings the POSLT to the meeting.	Advance care planning with POLST as a standard part of the admission process
We do have…some family members who are not comfortable, and it takes longer, and a lot of reassurance, you know, about why we're having the conversation now. [Y]ou know, in the event that mom or dad should have a decline, it's better to know up front what…the expectations are, and you know, what has mom and dad said that…they want…We have had that meeting and given them the POLST to go home and talk with the rest of the brothers and sisters about.	Talking to uncomfortable family members
I know at one point they were trying to…just have everybody have a POLST, and…then the hospitals were calling saying "Let's not do that because a lot of our staff…aren't educated on it, so let's stop." So, it's been back and forth.	Issues with POLST usage in hospitals
I wish there was…you know, you've got your…computer set up for…your Medicaid, if you want to check a Medicaid application you can. I think that would be beneficial to be able to do…for the POLST…[W]e had a resident that went out the other day and his POLST didn't make it with him. And then we've had some where we've sent out, well the POLST didn't make it back.	Desire for electronic POLST records
[W]e're very blessed that we kind of piloted the POLST and then we—most of our patients have them, whether they get it at the hospital or we do it when they are	Helpfulness to staff of having POLST in

admitted….I think it helps because you're not at the last minute trying to have that conversation with a family.	place in advance of resident decline
The way that I look at it, I guess for me, is always know that my main goal is to try to do what's best for the patient. And so [the POLST is] really the only way I can get their wishes carried through, you know. If it's a patient I can sit down and do the POLST with, then I can make sure that they have what they do and don't want done when the time comes. And that's really the only way they can continue to speak for themselves, 'cause that's my one thing…I want to try to speak for my residents when they can't, you know, speak for themselves. And the POLST is a really good way of doing that…It gives me comfort in knowing I'm doing what they would have wanted.	Taking comfort in knowing residents are receiving their desired level of care

Emphasizing Death as a Natural Process and the Importance of End of Life Comfort

In five interviews, staff explained that it is important to emphasize that dying is a natural process. One staff member described this as a crucial strategy in the discussion of end of life planning documents. For example, she explained, staff would say "allow natural death" not "do not resuscitate." A staff member from another facility explained that they always like to emphasize death as a natural process, not just to the family members and friends but to everyone within the facility. It is important to do everything possible to comfort dying residents and their families/friends and to celebrate the lives of the deceased. Another staff member explained that thinking of death as a natural part of life is helpful not only to her residents but to her personally.

Multiple staff members discussed the concept of allowing a natural death in the context of morphine use. During the last moments, LTC and hospice staff often use morphine to control pain and ensure comfort of dying persons. We spoke with three hospice chaplains who worked in the long-term care setting. They explained that before the final moments, they talk to family members about what they can expect. If family members request more or less morphine than what is needed to keep a resident comfortable, this may indicate a deeper anxiety and a need for additional conversation about the dying process. They discuss religious or spiritual matters with families that are so inclined, but they always focus on the natural process of dying and the importance of comfort. At another facility, LTC staff described having similar conversations with residents or even staff members who express concern with the levels of morphine provided. They tell the concerned party that it is all about comfort. They prepare people by explaining that breaths will get shorter, and they may eventually stop. They are not pushing the process of death, but instead facilitating comfort.

DISCUSSION

The Impact of End of Life Planning Failures on Family and Caregivers

End of life planning is frequently justified based solely upon its benefits to the dying. Terminal patients deserve the right to refuse life-sustaining treatment that will augment their pain and suffering, even if that treatment will extend their life. Less attention has been given to the impact that end of life planning can have on family members and caregivers. The impact of grief from losing a loved one is well-established;[11] however, in some cases, family members and caregivers suffer not only due to the death, but also due to the manner of the death.

This manuscript has described multiple cases in which plaintiffs sued medical providers who failed to honor the end of life wishes of their loved ones. They sued not only on behalf of their loved ones (as heirs), but also individually, arguing that they had personally suffered legally compensable pain. In addition to recovering for the pain that their family members had suffered, they were also entitled to compensation for their own pain and suffering. In each of the above-referenced cases, a court found that, as a matter of law, plaintiffs had pled sufficient facts to establish these claims, and the claims could proceed to a jury trial. As a result of these findings, defendants generally offered financial settlements to avoid a jury finding of culpability. Family members can suffer legally recognized damages when they see a loved one suffering unnecessarily in the final days, when they are berated by staff for wanting their loved one to die, when they witness the frustration of a loved one at the realization that her wishes were not followed, and when they are forced to affirmatively remove a life-sustaining apparatus, instead of merely "letting nature take its course."

LTC staff also describe the benefits to themselves and family members when pain is controlled and a decedent dies a peaceful death. One staff member explained that to her, the hardest part of a death is watching the dying person suffer, and that death can be a relief. This is consistent with findings in other qualitative studies cited in the systematic review of the literature.

In addition, staff experience extreme frustration when a person dies without documenting end of life preferences. One staff member explained that it's "almost like they don't have any rights." Another staff member explained that she derives satisfaction and comfort from helping a resident complete a POLST, thereby ensuring that her care preferences are respected. Like family members in the court cases, staff are upset if they do not believe that a person's end of life care wishes are being honored, and they derive comfort from knowing that they are.

POLST as a Tool to Promote End of Life Planning

The interviewees collectively discussed numerous benefits to using the POLST as a tool to promote end of life planning. Consolidating end of life planning documents to a single form would make it easier to discuss with residents. Instead of feeling bogged down with numerous pages of paperwork, staff can focus their attention on effectively communicating the benefits of end of life planning and describing the care options. One staff member described the POLST as “a quick form” to alert medical providers to care preferences. Staff also liked the variety of care options offered.

Staff found that the POLST is a good tool to help get family members and residents to think about end of life planning issues. They can talk to the individual about the form and leave the form with them to think about or discuss with other family members. Several staff members described the manner in which their facility had made POLST discussions a regular part of the admissions process. Staff either set aside time at the initial care plan meetings for POLST discussions or, in one case, set up separate advance care plan meetings that were conducted in addition to the regular care plan meetings. Usually the director of nursing, the social worker, or the director of admissions takes the lead role in explaining the form.

Interviewees also provided evidence of the inconsistency of POLST usage by hospitals. Although these interviews were completed while the POLST was still very new, there continue to be widespread reports of inconsistent usage of POLST within Georgia hospitals. Shortly after the POLST legislation was enacted, the Georgia Hospital Association (GHA) released a memorandum outlining several legal issues that they had with the POLST legislation in place and stated that as a result of those issues, metro Atlanta hospitals would accept but not promote it.[62] Subsequently, the POLST Collaborative worked with the Georgia Hospital Association to pass SB 109 in 2016, which addressed the association’s issues. For example, the provision granting immunity to doctors who follow the POLST in good faith was changed to explicitly include healthcare facilities and providers also.[63,64] Nevertheless, hospital usage of the POLST still varies widely in Georgia.

Courts across the country are finding that medical providers can be held responsible for not following patients’ end of life wishes, and numerous hospitals and LTC facilities have had to pay out settlements to avoid lawsuits. In most cases, the payout is undisclosed, but in two prominent cases, $1,000,000 was paid.[49,50] *Alicea* (one of the cases with a one-million dollar settlement) is particularly important in the state of Georgia from a legal standpoint, because it was appealed all the way to the Georgia Supreme Court. Since the Georgia Supreme Court is the highest court in Georgia, all other state courts are required to follow the precedential rulings set forth in this case. In other words, all courts in the state of Georgia are undisputedly and unambiguously required to allow claims for damages due to unwanted treatment to proceed.[57] *Alicea* should therefore put all Georgia medical providers on notice that they can face substantial liability for failing to implement documented end of life planning.

Nevertheless, there continues to be a strong belief within medical facilities that they can ignore patient preferences with impunity and leave the doctor to decide what is best for the patient. As increasing numbers of settlements and judgments become publicized, this policy is likely to eventually change. It is helpful when plaintiffs refuse to sign nondisclosure agreements and actively work to publicize information about settlements. Additional education and training of medical providers would also be beneficial in accelerating policy change.

The POLST is still a new document, and there is likely to be a learning curve and adoption curve with all new documents. Although all interviewees here who were familiar with the POLST found it fairly easy to understand, one staff member noted that it is a bit more complicated than the DNR, in that you have to go through and read all of the different options to determine a resident's preferences.

Discussing End of Life Planning with Families

Staff consistently told us that it is important to focus on death as a natural process when talking about end of life care options. One should not use the phrase "do not resuscitate" but instead talk about allowing a natural death. They should talk to family members about the importance of controlling pain, so that terminally ill residents can die peacefully.

For residents of LTC, end of life planning discussions should occur soon after admission. In 2016, CMS passed a regulation entitled “Comprehensive person-centered care planning.”[65] This regulation mandates that LTC facilities must develop a basic or comprehensive care plan for all residents within 48 hours of admission. All care plans must include a discussion of physician orders and of the resident’s “initial goals based on admission orders.”[65] As noted by several interviewees, these care plan meetings provide an optimal time to begin discussions of end of life planning and review any prior end of life planning that has occurred.

Outside of the LTC setting, physicians should conduct these discussions with patients in the later stages of life. Medicare Part B now covers “Advance Care Planning.”[66] This enables medical practitioners to discuss end of life planning decisions and assist patients in filling out documentation for them. Physicians may provide this care at no cost to the patient and bill CMS directly.[66]

Limitations and Potential Biases

Legal Study

This research was limited to cases in which defendant medical providers were accused of failing to follow end of life planning documentation and responded by filing a motion to dismiss or a motion for summary judgment. In some cases, defendants may have responded to a complaint by simply offering a confidential settlement. In those cases, there would be no court ruling related to the cases, and the cases would not be covered in this paper. In addition, defendants settle cases to avoid findings of culpability by a jury and to avoid disclosing to the public the amount that they pay out to victims. Thus, defendants never admitted culpability, nor was there a jury verdict indicating culpability. In many cases, it is impossible to determine the amount of the settlement, and in one case, I could not confirm for certain that a settlement occurred. Finally, this is not a traditional legal study. Instead of searching for and focusing on the most complex legal issues, I focus primarily on evidence of legally recognized pain suffered by bystanders and the increasing frequency with which medical providers are forced to pay out settlements. Thus, I did not fully explore all legal issues presented in each case.

Qualitative Study

As in all qualitative studies, participants cannot be selected randomly. All interviewees were volunteers who were willing to talk to us about their grief experiences. Before beginning our interviews, we informed staff about the topic and gave them the opportunity to decide whether they wanted to participate in an interview. In some cases, leadership suggested candidates that they thought would be comfortable speaking to us.

In selecting the interview transcripts to analyze, I used a process known as "purposive sampling." I selected interviews in which staff gave detailed descriptions of their experiences and recounted personal stories. I also ensured that my selection included staff from a variety of different facilities and from many different positions within the facilities (leadership, nursing, environmental services, etc.).

Despite the efforts to ensure diverse participation, the study may still be susceptible to selection bias. Some staff that suffered from severe grief symptoms may not have wanted to discuss them. Staff that felt less burdened by grief might have believed that they could not contribute to the conversation, and thus they may also have chosen not to participate. Finally, the facilities that chose to invite us to interview their staff might be those facilities that are more proactive in caring for their staff.

This study also has geographic limitations. All facilities were located in southern Georgia; however, the facilities were otherwise very diverse. I selected some interviews conducted in facilities located in a city with more than one hundred thousand people and other interviews conducted at facilities in a town with fewer than five thousand people. Nursing Home Compare rates all facilities, giving them between one star and five stars, and this study includes both one-star and five-star facilities (and facilities with ratings in between). The size of participating facilities also varied greatly, from 85 certified beds to 228 certified beds. Finally, the type of patients served varied greatly. For example, while most facilities had many residents who were eligible for Medicaid, there was one facility that refused to accept Medicaid, catering to a higher income population. Participating facilities also included one long term care acute hospital (LTACH) with staffing to support residents on ventilators and one facility that catered to residents with behavioral issues and clinical psychiatric diagnoses such as schizophrenia. To protect the privacy of our interviewees, we did not collect demographic data from them.

This qualitative study uses cross-sectional data: the interviews were taken at a single point in time. Thus, causal relationships cannot be positively established. To the greatest degree possible, I have eliminated bias from within the coding process. I have studied LTC grief for four years, and I had naturally drawn some conclusions before beginning this analysis. However, I created objective, written criteria for the application of each code within the interview. In addition, I had a second coder, with no prior experience in this field, double code my interviews to verify my objectivity. These are best practices in qualitative analysis.

CONCLUSION

Family members, caregivers, and friends of dying patients benefit from the use of end of life planning. When they see that the dying person is suffering at the end or not having his/her end of life wishes respected, this causes them greater pain. This dissertation provides evidence that this is true both for family members and for the LTC staff that care for the dying persons. The POLST is an effective tool to promote and facilitate end of life planning, and when used properly, it can help medical providers to avoid mistakenly providing unwanted treatment. However, inconsistent use of the form among medical providers limits its usefulness. Because the form is still relatively new, hospital and LTC staff may not fully understand how to use it. Increased training is needed to teach medical facility executives about the legal ramifications for failing to honor patient preferences and to teach staff how to successfully use the form. The latter training should include a discussion about the best terminology to use when discussing end of life planning. Death should be spoken about as a natural part of life, and phrases such as "allow natural death" should always be used in lieu of "do not resuscitate." Within the LTC setting, these discussions should begin at the initial care plan meetings.

CHAPTER 5

CONCLUSION

DISCUSSION OF THE FINDINGS

In Chapter 2, I completed a systematic review of the literature. Nineteen studies of staff grief, which included quantitative studies, qualitative studies, and mixed methods studies, formed the basis of the systematic review. They provided substantial qualitative and quantitative evidence, gathered between 2000 and 2019, of the effect that grief has on long-term care staff. Overwhelmingly, the studies showed that staff form a familial relationship with residents, and the multitude of deaths cause distress among staff. Staff frequently report burnout, which is commonly manifested through depersonalization of or detachment from residents. Most studies reported that grief is exacerbated due to a prolonged or painful death; a surprise death; a failure to memorialize the deceased; insufficient training surrounding death; close proximity of the death to other trauma; and/or an inability to provide the desired level of care due to a lack of time or resources.

At least two of the exacerbating factors suggested future areas of research. First, multiple studies described the close proximity of the death to other trauma as a factor that exacerbates grief. In most cases, this other trauma is the death of a loved one. This finding, along with my own work in the field, led me to examine cumulative loss in my own qualitative analysis. Second, staff frequently reported exacerbated grief due to prolonged or painful deaths. This finding, combined with my own research, led me to focus on end of life planning in my research. Prolonged and painful deaths are often avoidable through end of life planning; however, it is not discussed in the literature on staff grief.

In my second manuscript, I utilized transcripts from seventeen interviews with long-term care staff and the hospice chaplains who work with them. In this manuscript, I confirmed symptoms commonly described in the review of the literature, but I also documented new symptoms, such as physical symptoms, anger stemming from grief, and dwelling upon death. In addition, I documented cases in which grief stemmed from empathy with the family members. Often, staff empathized with those family members because they had experienced similar grief in their own lives. In some cases, staff relived the death of a parent after seeing a resident's family member undergoing a similar loss.

Next, I dedicated one domain of my coding frame to cumulative loss. I documented discussions of multiple losses in a short proximity. This proximity was not a specified amount of time, but instead I focused on staff perception. I was interested in cases where staff felt that they had experienced multiple deaths in quick succession. My analysis included excerpts in which staff described the emotional toll that these repeated deaths have had.

Finally, I examined factors that exacerbate grief. In addition to factors described in the literature review, I considered additional factors that I had seen through my work. For example, staff frequently suffered added stress around a death due to their interactions with grieving family members. People react differently to grief, and staff generally have not had any training related to interactions with grieving family members. For example, grief can take the form of anger, directed either at LTC staff or at other family members. In some cases, they may blame staff for the deaths. Families might also fight amongst themselves about issues related to care decisions or even the distribution of assets. Having to handle these differing family dynamics while undergoing their own grieving processes can be stressful.

Other commonly cited added stressors include difficult residents, extensive paperwork or bureaucracy, and particularly close relationships with the deceased residents. Staff members were generally very sympathetic to difficult residents, explaining that many residents become scared as they feel themselves declining physically and mentally. One staff member even gave a sympathetic description of a staff member who had both physically and verbally assaulted her. However, handling difficult residents is physically and emotionally exhausting.

In my final manuscript, I focused on the impact of end of life planning on family members and caregivers. For this manuscript, I undertook a novel mixed methods study: I combined legal and qualitative analysis. For my legal analysis, I examined cases in which end of life wishes had been documented but not adhered to by the medical providers. In each of the cases that I examined, the plaintiffs made claims for damages not only on behalf of their deceased loved one, but also on their own behalf. In each case, the court found that they had pled sufficient facts, as a matter of law, to recover damages.

The qualitative section of the study used data from the same transcripts as those in the second manuscript; however, it focused on end of life planning. In addition to discussions of end of life planning, I searched for descriptions of the benefits of end of life planning and the drawbacks to not having it. I also looked for best practices in end of life planning, which included use of the POLST and techniques for talking to families.

SIGNIFICANCE OF THE WORK

This work makes a substantial contribution to the relatively small body of work focusing on the impact of grief on long-term care staff. To the best of my knowledge, this work provides the first systematic review of the qualitative and quantitative studies that focus on staff grief.

This will serve as an invaluable resource to anybody seeking to understand the impact of grief in this setting.

After completing a systematic review, I sought to confirm and build upon the findings of other scholars. In addition to duplicating the findings of other scholars, I also found qualitative evidence of additional grief symptoms, cumulative loss, and added stressors. This work contributes to our understanding of staff grief.

Finally, I examined the impact that end of life planning can have on the grief of caregivers and family members. To the best of my knowledge, this is the first paper to directly examine this topic. In addition, before now, nobody has considered case law as a source of evidence of LTC staff grief. By combining evidence from case law and from qualitative interviews, I created a novel mixed methods study, which can be replicated by other scholars in the future.

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APPENDIX A

QUALITATIVE CODEBOOK

Domain	**Code**	**Code Description**
Grief Symptoms	Cry or inability to cry	Any staff expression of tears, crying, holding back tears, or being unable to cry.
Grief Symptoms	Burnout	Use for instances of staff depersonalization, burnout. May be used to explain a staff member's own behavior, the behavior of a co-worker, or how one should/should not behave when caring for residents Ex. burnout, a need for emotional distance, desire to avoid an emotional attachment with residents, talks about caring for or being able to feel things for residents (the opposite of burnout), emotional exhaustion, lacking a sense of personal accomplishment/ achievement/competence in their own work
Grief Symptoms	Empathy with grieving family	Used when staff interviewees express empathy for grieving family members or residents or instances where residents/ their grieving families remind staff of their own personal losses.
Grief Symptoms	Dwelling on the death or difficulty recovering for a long time	Only used when interviewee expresses intrusive thoughts of grief, an inability to stop thinking about the deceased, or notes a significant length of time for the grieving process. Pertaining to themselves or another staff member who confided in them.
Grief Symptoms	Physical symptoms	Physical representations of grief in the body. Use when a person conveys their own symptoms or discussing symptoms they noticed in another staff member

		(who is struggling with loss). Crying is not a physical symptom and is its own code. Ex. pain, nausea, headache, weight loss, fatigue/physical exhaustion, light-headedness, difficulty sleeping/insomnia, any decline in physical health following a death etc.
Grief Symptoms	Emotional symptoms	Emotional representation of grief by staff. Not to be confused with the physical representation. These codes have no physical representation Ex. depression, sadness, anxiety, overwhelming, difficulty concentrating, lack of control, intrusive thoughts reminding them of the deceased, emotional exhaustion (unrelated to work- if related to work, it will be coded as "Detachment, Depersonalization, Burnout"), difficulty eating (unless there are noticeable physical changes- then code as "Physical Symptoms"), etc.
Grief Symptoms	Other	Staff grief symptoms that do not fit into a named category
Cumulative Loss	Multiple family or friends	A staff member expresses grieving multiple friends/family members simultaneously.
Cumulative Loss	Multiple residents	A staff member expresses grieving multiple residents simultaneously.
Cumulative Loss	Personal and resident loss	A staff member expresses a cumulative effect of grief due to a personal loss (ex. family member/close personal friend) and the loss of a resident (with whom they have grown close to/consider a friend)
Cumulative Loss	Other	Any cumulative grief by staff that does not fall into one of these categories
Grief and Added Stressors	Angry, abusive or difficult resident (physically or verbally)	A person engaging with an angry, abusive, or otherwise difficult resident.

Grief and Added Stressors	Administration of morphine	A staff member expresses discomfort/concern regarding the administration of morphine, or other drugs at the request of a family member and/or based on a physician's order
Grief and Added Stressors	Lack of training to deal with families	Staff expresses an insufficient amount/quality of training from a facility to engage with families during/after a resident death.
Grief and Added Stressors	Family Dynamics	Use this code anytime family dynamics are discussed negatively. This includes instances when family members are angry at staff, angry with each other, do not get along, or do not seem to genuinely care about the family member (may be family members who do not visit, are overly concerned with material possessions, etc.)
Grief and Added Stressors	Other frustrations due to rules, regulations, required paperwork, or the Medicare/Medicaid payment structure	Staff member expresses frustration with rules, regulations, policies, procedures, paperwork. Also use when a person expresses frustration or confusion surrounding Medicaid or Medicare payments
Grief and Added Stressors	Care for the self	A staff member expresses positive benefits of or difficulty maintaining/achieving effective self-care.
Grief and Added Stressors	Underappreciated/ experience questioned, especially related to EOL residents	A staff member feels under-appreciated or someone doubts/questions their clinical experience, especially their ability to provide palliative care to EOL residents.
Grief and Added Stressors	Not knowing how to deal with body or death for first time	Staff lack emotional and/or procedural preparedness in terms of what to expect from a dead body and/or how to handle it.
Grief and Added Stressors	Staff notification of death	Staff aren't notified before coming into the workplace that a resident has passed away.

Grief and Added Stressors	Relationship between staff and the deceased	Use when a staff member reports developing a familial/friendly relationship with a resident and feeling increased or aggravated grief when the resident suffers/dies.
Grief and Added Stressors	Stressors outside of work	Use this when a stressful or difficult situation outside of work affects staff at work. For example, staff member is caring for sick relative at home.
Grief and Added Stressors	Other	Added stressor that does not fit into any code
End of Life Planning and Grief or Stress	Staff grief alleviated due to good (calm, peaceful) death	A person expresses less stress/grief due to an easier/good/calm/peaceful death.
End of Life Planning and Grief or Stress	Stress due to repeated painful and ultimately futile life-sustaining measures	A person expresses sadness/stress regarding multiple or severe instances of life-sustaining measures (ex. CPR).
End of Life Planning and Grief or Stress	No clear decisionmaker or Uncertainty	Use this code when staff are uncertain about which family member is permitted to make end of life decisions, are uncertain about what type of end of life care should be administered, or no pt. representative (familial or legal) has been appointed.
End of Life Planning and Grief or Stress	Family strife around end of life care	Use this code when staff witness families fighting among themselves near the [resident's] end of life.
End of Life Planning and Grief or Stress	End of Life Planning/discussions	Any reference to the POLST, advance directive, or any other end of life planning document. This code may also reference conversations surrounding EOL decisions.
End of Life Planning and Grief or Stress	Other	Use this code for anything related to end of life planning and grief or stress that does not fit into the other categories.
Best Practices	End of Life Comfort or Emphasizing	Use this code for any instance where people emphasize or suggest emphasizing (as a policy/procedure) the

	dying as a natural process	natural process of dying. Also use this when a person emphasizes or focuses on the benefits of making an individual comfortable at the end of life.
Best Practices	POLST forms	Use when people discuss availability/easy access/obstacles to using POLST forms.

APPENDIX B

CODING RESULTS

Category Referenced in Interviews	Number of Interviews	Total Number of References
Grief Symptoms		
Cry or inability to cry	14	20
Burnout (including explicit references to burnout or to a scale on the Maslach Burnout Inventory)	12	25
Empathy with grieving family	11	29
Dwelling on or difficulty recovering from death	7	15
Physical symptoms	4	4
Emotional symptoms	17	47
Cumulative Loss		
Multiple family or friends	6	6
Multiple residents	5	7
Personal and resident loss	5	8
Grief and Added Stressors		
Angry, difficult, or abusive residents	6	16
Family dynamics	14	40
Issues related to administration of morphine	3	6
Frustration due to rules, regulations, paperwork, or Medicaid/Medicare payment structure	7	33
Failure in staff self-care	5	13
Feeling underappreciated or having one's abilities Questioned	2	5
Not knowing how to deal with body or death for the first Time	2	2
Relationship between staff and the deceased	12	28
Lack of training to deal with families	1	5
Stressors outside of work	3	5
Staff notification of death	1	1
End of Life Planning		
Staff grief alleviated due to good (calm, peaceful) death	3	3
Stress due to repeated painful/futile life-sustaining Measures	2	3

No clear decisionmaker/uncertainty about EOL decision	2	4
Family strife around end of life care	1	1
End of Life Planning documentation or discussion	12	46
Best Practices Related to End of Life Planning		
Use of POLST	12	35
End of life comfort/Emphasis of death as natural process	5	9

APPENDIX C

INSTITUTIONAL REVIEW BOARD APPROVAL

Phone 706-542-3199

The University of Georgia

Office of the Vice President for Research
Institutional Review Board

APPROVAL OF PROTOCOL

March 10, 2016

Dear Toni Miles:

On 3/10/2016, the IRB reviewed the following submission:

Type of Review:	Initial Study
Title of Study:	Changing the Culture of Death and Dying in the Nursing Home Setting: Pre-bereavement planning and POLST Discussions.
Investigator:	Toni Miles
IRB ID:	STUDY00002814
Funding:	Name: TBD;
Grant ID:	

The IRB approved the protocol from 3/10/2016.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103).

Sincerely,

Dr. Gerald E. Crites, MD, MEd
University of Georgia
Institutional Review Board Chairperson

310 East Campus Rd, Tucker Hall Room 212 ◆ Athens, Georgia 30602
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