Caregiving for the Dying: An Exercise in Compliance or Agency?

Dissertation

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Abstract

Dying is one of the few universal social experiences humans face and despite this ubiquity we lack deep understanding of how the contours of dying are navigated by all actors in the process. While the major task of sociological research, health social movements, and the actions of medical professionals has focused on improving the options available to and experiences of dying persons (a decidedly worthy cause), there has been considerably less focus on how the experience unfolds for familial caregivers of the dying. This dissertation explores how familial caregivers of persons in hospice navigate care, specifically interrogating how agency over the care context is not and is exercised. Data come from twenty-five semi-structured in-depth interviews with familial caregivers of persons enrolled in hospice within the past three years. Interviewees were asked questions within the broad categories of caregiving activities, interactions with family members while caregiving, interactions with medical professionals, and their general understanding of death and dying more broadly.

From this effort I first sketch out three distinct caregiver archetypes respondents used to guide their approach to care. These archetypes included the unbiased ally, the deferential supporter, and the unbewitting bystander—all of which conveyed some degree of compliance with outside influences (typically the wishes of the dying person) that guided how care is to be ideally navigated. Secondly, I begin to explore how respondents exerted influence over the care context, albeit in limited ways, through subtle care correction. Subtle care corrections occurred in response to a care impropriety committed by another caregiving actor and subtle corrections were launched toward medical professionals and family members. Respondents described the subtle nature of their corrective efforts as the result of considering or protecting specific family members or general family dynamics in some way. These results illustrate that correcting care improprieties occurred but were approached in a subtle manner because of familial constraints. Finally, I interrogate the limited instances in which clear agency in the caregiving context was exercised. I explain these direct agentic actions through respondents use of *mortality beliefs*, a concept pioneered in this study that describes the values so strongly held by caregivers of the dying that agentic action was inspired. Mortality beliefs encompassed investments in preserving identity, seeking objectivity, and ensuring justice.

Together, these findings contribute to our understanding of how familial caregivers of the dying—key actors in the dying process—navigate care. These findings first detail the multitude of influences that come to bear on how care for the dying is set up as an exercise in compliance. They then tell of how caregivers begin to claim agency over the care context and their experience. This exploration of compliance and agency as it manifests in EOL care highlights the dual dimensionality of agency as simultaneously positive and negative for caregivers of the dying.

Dedication

For Dad and Ricky—

You taught me loss because you had to and love because you wanted to.

Acknowledgments

To my respondents, who shared with me the most difficult experiences of their lives with beautiful intention and insight. To say “thank you” is not enough.

All of the important things I have learned in the course of this degree are because of Rin Reczek and their unrelenting commitment to making me the most qualified, critical, and productive scholar and human. Rin spared no opportunity to tear apart my writing (and help me rebuild it better than before), talk through complex theoretical and methodological quandaries, and celebrate the small wins of academia. For all of these efforts I am forever grateful.

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Publications

2020	Reczek, Corinne, Mieke Beth Thomeer, Lauren Gebhardt-Kram, and Debra Umberson. 2020. "'Go See Somebody': How Spouses Promote Mental Health Care." Society and Mental Health 10(1):80–96. doi: 10.1177/2156869319834335.
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Fields of Study

Major Field: Sociology

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Chapter 1. Introduction

A major aim of the American hospice movement was to dissolve death's status as a taboo subject in popular thought (Livne 2014). To this end, introduction of the modern American hospice system occurred in the early 1970's by way of a British nurse-turned-medical-social-work-practitioner named Cicely Saunders (Clark 1998). In her professional work, Saunders recognized a dearth of care offerings for the dying and to address this deficit, she developed a model of intervention called *hospice.* This new model for death and dying focused on the joint task of providing care to the dying *and* their family members because death is not just experienced by the dying alone, it is also experienced by those close to the dying (Shapiro 1996).

For sociology's part, in matters of end-of-life (EOL) great care has been expended to better understand EOL processes for a multitude of actors and outcomes in the dying process. Research endeavors of this kind tell of the ways death and dying is navigated by medical doctors, dying persons, and familial caregivers of the dying. For example, upon a terminal diagnosis, findings reveal mixed involvement from medical doctors who may only engage in short conversations about death/dying with their patient (an average of 6 minutes according to Keary and Mooreman 2015) or they may spend considerable effort empowering the dying and their family during EOL decision making (Livne 2019). Other research finds that dying persons variably elect to complete advanced care directives that make clear to caregivers their EOL wishes (Seelman et al 2019), and familial and medical caregivers variably honor those wishes (Abadir et al. 2011).

Moreover, research in this area tells of the various quandaries and negative outcomes associated with the dying process. Quandaries arise such as in weighing the pros and cons of facility or home hospice (Townsend et al. 1990), how family members can appropriately advocate for quality care of their loved ones (Gengler 2015), or debates about patients and their right to die (Buchbinder 2018). Furthermore, much has been explored about the arduous nature of caregiving for a dying loved one (for example, see Isaksen 2002) and its negative physical and mental health consequences (Morgan et al 2016; Northhouse et al 2012). The cumulation of these sociological efforts understandably centralize the dying person. This is reasonable because death carries a sense of irrevocability—how the dying process unfolds cannot be undone at its conclusion. Because of this, dying persons have the most to gain from understanding death and dying, thus improving their situation is prioritized. However, centralizing dying persons risks compromising our understanding of the expectations and limitations placed on familial caregivers of the dying.

With sociological findings of how variably death is navigated and how certainly it is negatively experienced (at least in some way) by caregivers, the situation of caregivers of the dying presents a unique context in which to view sociological processes of how external forces come to bear on individual experiences and vice versa. This unique opportunity exists for several key reasons. First, the sense of immediacy and finality of death pushes individuals to make sense of a seemingly order-less life course stage, thus individuals welcome external forces to guide their experience. Second, EOL negotiations are inherently social as they involve multiple actors including the dying, family of the dying, and medical and hospice professionals. These relationships have the potential to be concordant or discordant in pursuit of order, thus opening a window into how power itself is exercised.

Because of the monumental potential presented by better understanding the situation of caregivers of the dying, the current research has aimed to more fully account for their experiences. In empirical chapter one I ask, (1) what do family caregivers expect their role to be when they begin caring for the dying? and (2) what are the external forces that shape how expectations of care become the tangible care they provide? In empirical chapter two I ask, (1) who do family caregivers of someone in hospice subtly correct care improprieties? And (2) what motivates a subtle approach to care correction? Finally, in empirical chapter three I ask, (1) how do caregivers of the dying explain their choice to exercise agency in the care context? And (2) What social values are reflected in the exercises of agency performed by caregivers?

Methods and Methodology

Data

Data for this project come from The Ohio End of Life Study, an in-depth interview study conducted in Ohio. The primary aim of The Ohio End of Life Study was to understand death and dying from the vantage point of family caregivers of the dying. Data collection began in Summer 2019 and continued through the end of Fall 2020. Twenty-five interviews with familial caregivers of the dying were collected in total; all interviewees were Ohio residents with most residing in one of the state's major cities (Columbus, Cincinnati, Cleveland metropolitan areas). Twenty of these interviews were collected prior to the COVID-19 pandemic. The remaining five interviews were collected after state lockdowns were in place and as a result these interviews were conducted over the phone, zoom, or facetime depending upon the respondent's preference.

For two primary reasons, the sample size of twenty-five interviews was deemed the appropriate amount given the goals of the study. First, at twenty-five interviews data saturation was reached. Data saturation refers to a consistent reptation of information across interviews (Sandelowski 2008). Second, with the current sample size theoretical saturation, which refers to the satisfactory repetition of conceptual properties and dimensions such that the complexity and variation of a given concept is captured, was achieved (Sandelowski 2008). In accordance with the standards of qualitative family research, sampling decisions should be "rooted in epistemology, theory, and richness and quality of data", all of which were honored in the present study (Roy et al. 2014).

Eligible participants were required to be at least 18 years of age and have been the caretaker of a person who received hospice care within the past three years. Limiting eligibility according to proximity to the caregiving experience allowed me to collect vivid stories of how caregiving unfolded because respondents were able to recall great detail within that time frame. Respondents were recruited through various methods including posting flyers throughout the city, on social media accounts for the study, and public forums such as university sponsored databases for research participants. Enrolled respondents also referred other participants to the study on occasion. Such varied methods of recruitment were used in effort to increase sample diversity in terms of socioeconomic status and race. Participants were given a $20 gift card for participation. Interviews were conducted by the submitting author only and interviews averaged 90 minutes in duration (although they ranged from 45 minutes to 2 and a half hours).

Before the interview, each participant was required to complete a baseline survey collecting data on basic sociodemographic characteristics such as age, socioeconomic status, race, care-receiver's time spent in hospice, and whether hospice care occurred in the home or in a facility. Data from the baseline survey are displayed in Table 1. Note that one participant (Michaela, interviewed after the start of the pandemic) failed to return baseline data, thus information that was directly answered during the interview was entered in Table 1 by the author. All descriptive information provided hereafter are of the twenty-four participants with more complete baseline information. The average age of respondents was 45.75 years old and ranged from twenty to seventy years of age. Fifteen respondents identified as non-Hispanic white, one as Hispanic white, five as black or African American, one as multi-racial, one as Asian/Pacific Islander, and one as "other". Eighteen respondents identified as women and six identified as men. Most commonly, respondents were the child of the person in hospice they cared for (n=14) and spousal caregivers were found in only two of the interviews. For highest level of education nine participants completed some college, ten were college graduates, and five had post-graduate degrees. More detailed information on marital status, personal and household income, current or most recent employment, and disease resulting in hospice care can be found in Table 1.

During the interview, respondents were asked to discuss their caregiving activities, interactions with family members while caregiving, interactions with medical professionals, and their general understanding of death and dying more broadly. The full interview guide is included as Appendix A. During the interview respondents were encouraged to determine what types of information to discuss thus allowing the most salient information to arise.

Analysis

A standardized method of inductive data analysis emphasizing the dynamic construction of codes to develop analytical and theoretical interpretations of qualitative data were used (see Silverman, 2005). In particular, I used a flexible coding approach (Deterding and Waters, 2018) that began with sorting the data into broad codes determined by the type of question asked in the interview. From these broad codes, analytic memos were written to expand on the concepts and theories emerging in the data. This approach provided a useful alternative to strict grounded theory because of its compatibility with qualitative analysis software, such as Nvivo. Such an approach assumes qualitative projects using a combination of inductive and deductive analysis techniques, yielding analyses that “facilitate reliability, validity, and transparency” (Deterding and Waters, 2018). Nvivo qualitative software was used to house and organize the data only; no Nvivo programs were run to code the data.

Using this approach, I first conducted line-by-line, data driven categorization of the interview information to summarize each piece of data as it related to the caregiving experience. Second, I developed focused codes regarding caregiver architypes (first empirical chapter), instances of subtle care correction (second empirical chapter), and mortality beliefs that related to caregiver agency (third empirical chapter) by connecting initial line-by-line codes together conceptually. Finally, I created conceptual memos to develop the focused codes into categories and sub-categories that related to each other theoretically. Presented in this dissertation are the themes from this final stage. Using one primary data analyst is part of a standardized qualitative methodology that draws on an interpretivist and constructivist epistemology (Roy et. al. 2015). Systematic and rigorous interpretation of conceptual findings by one data analyst is a highly reliable and valid approach to qualitative research (Esterberg, 2002).

Overview of Chapters

This dissertation presents an exhaustive account of the expectations and limitations placed on familial caregivers of the dying as they perform EOL care. Their stories begin in the first empirical chapter with how external forces became the caregiver architypes they adopted to help them understand their role in the dying process, progress to the second empirical chapter that explores the motivations behind subtle care corrections that constitute caregiver actions of exerting (limited) control over the care context, and finishs with the third empirical chapter that outlines the deeply held values that inform agentic action. Together, these chapters tell of the instances of compliance and agency contained within the EOL caregiving experience.

In empirical chapter one on caregiver archetypes, respondents fell cleanly into one of three archetypes that included the unbiased ally, the deferential supporter, and the unbewitting bystander. Unbiased allies viewed their role in dying as one of genuine collaboration where their personal wishes had no place in caregiving. Rather, their duty was to provide care that was completely under the purview of the dying person. Deferential supporters similarly privileged the wishes of the dying but lacked a sense of unfettered collaboration. Instead, deferential supporters held sometimes dissenting opinions about care, but ultimately, in action they carried out the wishes of the dying person without disagreement. Unbewitting bystanders were unique from the other two groups because outside forces attempted to censure their caregiving either in part or in whole. Despite these attempts, unbeweitting bystanders found ways to contribute to caregiving in meaningful ways. Together, these architypes illustrate the expectations caregivers absorbed to help guide their efforts and how those efforts centralized the dying person in ways that left caregivers largely powerless through processes of unbiased involvement, deferential decision making, or unbewitting exclusion.

Although caregiving was overwhelmingly characterized by care acts in accordance with the caregiving archetypes and their associated powerlessness, the second empirical chapter explores the few instances in which caregivers exerted (constrained) influence over the care context. This influence took the form of subtle correction of others' caregiving efforts that resulted when a respondent noticed a clear care impropriety (such as improper giving of medication or care negligence). Subtle correction in this context refers to any modifying effort that was *intentionally* limited and/or not pursued in a way that produced any change to the care plan. This most commonly took the form of not directly addressing the person performing an infraction *or* the improper caregiving action itself. All subtle corrections exhibited an effort to improve the quality of care received by the dying. Further, subtle corrections were directed toward medical professionals and other key familial caregivers. When subtly correcting a medical professional, caregivers indicated a general consideration of family dynamics for informing why a subtle approach was used rather than a possible overt approach. Regarding family members, caregivers indicated distinct motivations behind a subtle approach applied to lateral (i.e., intragenerational) and lineal (i.e., intergenerational) family members. Subtle corrections of lateral family members occurred as a means of protecting a family member or family dynamic. Subtle corrections of lineal family members occurred as a means of altering the correction receiver's involvement in care (such as by increasing their care contributions). Together, results from this chapter illustrate that correction in the context of care for the dying occurs, but that those corrections take on a subtle quality because of family. Further, the findings suggest more complex care correction and engagement processes exist beyond what is represented in current literature. Namely, although the existence of subtle correction has been previously established in patient and provider dyads or spousal dyads, findings on EOL care illustrate how and why a dyadic correction is related to actual care interactions with care actors outside of the correction dyad.

While the first two empirical chapters explore dimensions of how caregivers are constrained by outside forces, the final empirical chapter tells of their empowerment. This chapter interrogates the relationship between the agency caregivers claim over the care context as it relates to larger values they hold. To this end, this chapter pioneers the concept of *mortality beliefs*, or the values so strongly held by caregivers of the dying that agentic action was inspired. Specifically, mortality beliefs describe investments in preserving identity, seeking objectivity, and ensuring justice. Findings for mortality beliefs mirrored expectations set by previous research in most ways: valuing identity mirrors American individualism, valuing objectivity mirrors the tenants of evidence-based medicine, and valuing justice mirrors the motivations behind health social movements, making these findings generally predictable. However, unpredicted was *how* respondents would leverage agentic action to reinforce these values. Specifically, respondents were indiscriminate in who they enacted agency to benefit, sometimes being agentic for the dying persons' benefit and sometimes for their own. This is not to suggest that respondents were haphazard in applying their agentic action. Quite the opposite was true, respondents were exceedingly deliberate in choosing when and when not to exercise personal agency, most frequently erring on the side of passivity (as seen in the first two empirical chapters).

Together, empirical chapters one and two tell of the myriad of ways in which caregivers of the dying claim no or little agency within the care context, while empirical chapter three provides concrete understanding of the agency that can be found in care for the dying. Jointly, these findings illustrate elements of both compliance and agency that can be found among the experiences of caregivers of the dying. Compliance in this context (whether willing or not) affords caregivers the benefits of accessing a template for how to navigate care during a time of acute normlessness and the ability to protect desired family dynamics. At the same time, agency in this context allows caregivers to protect deeply held EOL values, or mortality beliefs.

Table 1. Sample Baseline Information

Name	Age	Race	Gender	Rel. Status	Occupation	Highest Level of Education	Personal Income	Household Income	Rel. to dying	Disease resulting in hospice
Amira	20	other	Woman	Single	Student	Some College or technical School	1-24.999k	N/A	Child	Organ Failure
Ayaan	23	Black or African American	Woman	Dating	Medical Assistant	College graduate	1-24.999k	50k-74.999k	Cousin	ALS
Benjamin	40	Black or African American	Man	Married	Engineer	College graduate	75k-99.999k	same as personal	Nephew	Dementia
Bobby	52	White	Man	Divorced	Disabled	Some College or technical School	1K-24.999K	same as personal	Child	Salivary Gland Cancer
Brandon	45	Black or African American	Man	Single	Systems Administrator	College graduate	50k-74.999k	same as personal	Grandson	Heart Disease
Brooke	51	White	Woman	Married	Designer	College graduate	75k-99.999k	100k-149.999k	Child	Pancreatic cancer (dad); Stroke (mom)
Catherine	59	White	Woman	Married	Registered Dietitian	Post-Graduate or Professional	150k or above	same as personal	Child	Dementia
Cassie	23	White	Woman	Dating	Graduate assistant	College graduate	1-24.999k	same as personal	Child	Cancer
Jenna	66	White	Woman	Cohabiting	Field Assessor	College Graduate	50k-74.999k	75k-99.99k	Ex sister-in-law	Ovarian Cancer and Geoblastoma
John	70	White	Man	Widowed	Retired	Some College or technical School	25k-49.999k	same as personal	Spouse	Cancer
Karen	60	White	Woman	Married	Expense Payable Supervisor	Some College or technical School	50k-74.999k	150k or above	Child	Dementia
Kim	45	White	Woman	Married	Professor	Post-Graduate or Professional	N/A	N/A	Daughter-in-law	Dementia
Lena	26	White	Woman	Single	Student	College graduate	1-24.999k	same as personal	Child	Cancer
Mandi	61	White	Woman	Married	Retired	Post-Graduate or Professional	25k-49.999k	150K or above	Child	CHF, kidney disease, diabetes
Michaela	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Child	Heart Disease
Naomi	59	White	Woman	Married	Registered Nurse	Some College or technical School	25k-49.999k	150K or above	Child	Breast Cancer
Rachel	43	White	Woman	Single	Housekeeper/ PC work	College graduate	1K-24.999k	$50-74.999K	Daughter	Lung cancer- stage 4
Rae	40	Black or African American	Woman	Widowed	Manuscript Editor	Some College or technical School	25k-49.999k	same as personal	Niece	Heart Disease
Rosa	35	Hispanic/Latino; White	Woman	Cohabiting	Accounting Specialist	College graduate	50k-74.999k	100-149.999K	Child	Cancer
Sam	40	Multi Racial	Woman	Married	Assistant Director of Nursing	Some College or technical School	50k-74.999k	75k-99.999k	Daughter-in-law	Necrotizing Fasciitis
Sandy	65	White	Woman	Widowed	Registered Nurse	College graduate	75k-99.999k	same as personal	Spouse	Prostate Cancer
Stefan	24	White	Man	Cohabiting	Grad Student	Post-Graduate or Professional	25k-49.999k	50k-74.999k	Child	Prostate Cancer
Teresa	37	White	Woman	Single	Business- Construction	Post-Graduate or Professional	50K-74.999K	same as personal	Grand daughter	Dementia
Tony	47	Asian/Pacific Islander	Man	Married	Senior operations manager	Some College or technical School	50k-74.999k	75k-99.999k	Child	Cancer
Vanessa	67	Black or African American	Woman	Married	Retired	Some College or Technical School	25k-49.999k	50k-74.999k	Child	Dementia

Chapter 2. Care for the Dying and the False Promise of Agency: Family Caregivers as Allies, Supporters, and Bystanders

Introduction

Initiating hospice care marks a clear transition from care provided primarily by medical professionals to care provided primarily by family members (McFarlane & Liu 2020). Despite this monumental shift, surprisingly little is known about the overarching strategies family caregivers of the dying use to navigate their new role (McFarlane & Liu 2020). Looking to research on medical professionals who transition care, what the dying wants the role of family to be and what family want their role to be in the dying process yields an incomplete view of how familial care is *actually* carried out and *why*. The hospice model is predicated on the transition of care away from formal medicine to familial care and this dynamic frequently holds regardless of whether the hospice recipient receives care in a home or facility setting. At end-of-life (EOL), medical professionals defer to the dying person and their family equally in how care should be enacted. Dying persons wish for care to be executed in ways that preserve their sense of independence and autonomy and family members wish to be intensely involved in all aspects of their loved one's care (Isaksen 2002; Tarberg et al. 2019). Conflictual care plans and family dynamics arise from this juxtaposition of wishes for autonomy and intense involvement from different key members in the hospice care process. Thus, hospice care represents a context of potential care conflict with implications for agency of actors and this has yet to be explored empirically.

To address this gap and to yield insight into complex care processes with implications for our understanding of agency, I ask (1) what do family caregivers expect their role to be when they begin caring for the dying? and (2) what are the external forces that shape how expectations of care become the tangible care they provide? To answer these questions, I use in-depth interview data from 25 individuals caring for a family member in hospice. While my respondents were asked many questions about various aspects of caregiving spanning from when their family member became sick to after they died, this paper focuses on instances of instrumental care my respondents provided (or attempted to provide). These responses indicate that external forces guide both their overall approach to caring for the dying and how this approach becomes the care they enact.

The data reveal distinct approaches to care that are created and reinforced by expectations external to the caregiver, most frequently generated by messages from the dying person themselves or other key familial caregivers. In adopting these outside messages, caregivers of the dying took on one of three primary approaches, becoming either the unbiased ally, the deferential supporter, or the unbewitting bystander. Unbiased allies approach care with an eye toward unencumbered collaboration, while deferential supporters and unbewitting bystanders develop their own, often conflictual, desires for the care plan. While all respondents desired to be as helpful as possible in their caregiving, these differing approaches constrained their ability to exercise agency over the care processes they were charged with and deeply invested in, with differing consequences and implications for agency by approach.

Background

Missing from our current understanding is how family members of someone in hospice come to navigate their new role as a caregiver for the dying. Detailed accounts of hospice and the desired transition from medical to familial care exist but lack depth of understanding of how this actually occurs from the perspective of family caregivers. Looking to research on this transition from the perspective of medical professionals, in conjunction with research on what dying persons and their family caregivers wish the role of family to be, and the conflictual care dynamics that result is helpful, even if incomplete.

Medical professionals transitioning care to the family

Foundational to the U.S. hospice model is residential hospice infrastructure paired with the expectation that families are both willing and able to execute near total care at EOL (Braswell 2019). With this model, medical professionals transition away from being main caretakers for the terminally ill and toward supporting the caregiving efforts of family. The perspective of family members compliments this structural-institutional expectation of familial care negotiation in relation to the diminished role of hospice medical professionals. Family caregivers identify the main role of hospice personnel as providing instrumental *support* through *guidance* and physical *presence* (Cagle and Kovacs 2011).

Although existent studies do not fully address the nuances of how the transition from medical to familial care occurs (Hudson 2005), there is overwhelming evidence that the transition to care results in prominent care provided by family regardless of whether hospice occurs in the home or in a facility. Using clinical observation and interview data from EOL facility and home care to understand what information was conveyed by medical staff to family caregivers upon entering hospice care, Lavalley (2018) finds that families using in-home hospice most frequently received information about patient mobility, medication uses and schedules, and nutritional needs. This stood in contrast to family members providing care in an institutionalized care context who received information on how to navigate transitions of care generally, and the logistical and financial considerations of care in particular (Lavalley 2018). Thus, even in instances of institutionalized care where one might presume decreased involvement from family, the care plan is still overwhelmingly under the purview of family.

Additionally, supporting evidence of the transmission of care, by taking a cue from research on how medical professionals help achieve a “good death” (see full discussion of the good death in the introduction to the dissertation), we see a general, and equal, deference of medical professionals to the will of the patient *and* family caregivers (Good et al. 2004). Taken together, there is much evidence suggesting that medical professionals view the role of family to be prominent in caregiving, and in most cases prominent enough to supersede the involvement of medical professionals themselves. Said differently, it appears that medical professionals come to view the role of families in caregiving as the main guiding force of care. Thus, medical professionals create the context in which dying persons and their family must understand, structure and, execute EOL care largely amongst themselves.

What the dying wants the role of family to be

Much of what is known about a dying person's expectations regarding family involvement in caregiving is from research on EOL decision making, and the decision to enter home or institutionalized care in particular. In general, among late-in-life individuals, the majority prefer to make EOL decisions independently and cite reducing potential burden to family as a motivating factor for this approach to care planning (Moorman 2011; Broom and Kirby 2013). Further, late-in-life individuals in the Wisconsin Longitudinal Study (a sample of 4,500 white midwestern adults in their mid-sixties) indicated this motivation for autonomy and independence in decision making was so strong, that persons at EOL rarely relax their hold on autonomous decision making (Moorman 2011). In fact, individuals at EOL only lax this expectation in extreme circumstances. For example, only when presented with the hypothetical scenario of unconsciousness were people at EOL willing to allow for their previously stated wishes not to be followed by medical staff in favor of family's' wishes (Puchalski et al. 2000; Terry et al. 1999).

Many studies corroborate these findings of independence in order to not burden family, most frequently by choosing care plans that involve medical professionals more prominently than familial caregivers, and regardless of whether care is institutionalized or in the home (Hudson 2006; Broom and Kirby 2013). Among EOL patients in institutionalized care, most state a preference to die at home (Townsend et al. 1990).

However, those who decide to enter institutionalized versus home hospice do so as a way to mitigate potential burden to family, particularly as it relates to caregiving. More specifically, those choosing institutionalized care facilities do so to benefit family members by giving them the break to go home and cope rather than facing the dying person and their care around the clock as would be the case with home care (Broom and Kirby 2003).

What family members want their role to be

Despite late-in-life individuals' desires for independence to avoid burdening family, the transition to hospice care marks decreasing involvement of medical professionals and a corresponding increase in care provided by family members. This transition in care marks a critical moment for families looking to establish their new role on the care team. While there is little to no research on exactly what family caregivers think their role should be and why, previous research shows that family members often do interact with medical staff and the dying person in particular ways. Most notably, in relation to medical staff, family members beginning EOL care for a loved one see themselves as the main caregivers (McFarlane & Liu 2020).

Family caregivers of the dying expect their role as caregivers to be heavily colored by more intimate forms of care (Generous and Keeley 2014; Isaksen 2002). Family involvement in intimate care occurs because family is seen as able to more effectively offer the care receiver emotional labor that reduces potential loss of dignity in the care context. Specifically, in instances of bodily decay (instances of deterioration of organ and other physical capacities), family members are able to draw on their previous relationship with the care receiver and execute the emotional labor of knowing what care to give and how to approach it in a way that increases the care receiver’s sense of dignity, integrity, and respect (Isaksen 2002). Perhaps also due to their rich relationship with the care receiver, family members also see themselves as best equipped to address issues of pain management of their loved one at end-of-life (Abadir et al. 2011; Hauser 2006). Family caregivers are often so dedicated to the immersive care of their loved one, that they position daily activities of their own life’s functioning as able to be done after the death has occurred (Generous and Keeley 2014). Further, this expectation of main caregiver carries even after the death of the caregiver occurs. Families see themselves as wholly responsible for eventual death and funeral logistics (Generous and Keeley 2014).

Conflicting care plans

With dying persons’ deep desire for an autonomous EOL experience that does not burden family and family’s strong desire to care for even the most intimate needs of their EOL loved one, the potential for conflict in the care plan is great. In studying care discordance between family caregivers and dying persons, Hauser (2006) finds differences between the two groups’ characterization of care needs and physical symptoms, and fears for the future and their general concordance on these issues reaching only between 53 and 66 percent. About half of those studied disagreed on the amount of physical pain experienced by the dying person, with family caregivers more likely to report higher pain levels than the dying person actually experienced. Further discordance was seen in reported need for increased formal care for the dying person. Specifically, patients reported more need for formal care than their family caregivers did with 42.6%

of the sample disagreeing on the issue. Finally, after being asked of the major fear facing the dying person the two groups differed greatly in their reports. Dying persons were more likely to cite fears of dependance and being a burden to family (182 person-endorsements) and using up family money (205 person-endorsements), compared to family members who endorsed the same fears (75 and 44, respectively). Thus, Hauser's (2006) work shows that the differing expectations of care involvement from the perspectives of dying persons and their family explored in the previous sections do indeed result in conflictual care plans upon beginning EOL care.

Observations from medical professionals also illuminate conflictual family dynamics in executing EOL care. In a case study of two daughters caring for their dying mother, the mother's medical doctors reflect on the care disagreements that occurred between the daughters and their dying mother (Abadir et al. 2011). In particular, the dying mother had a documented do not resuscitate (DNR) order that the daughters wanted to ignore. When medical staff made reminded the daughters of their mothers' wishes, one responded "I don't want to hear that. They don't know my mom like I know my mom" (Abadir et al. 2011, p. 2339). This highlights family members' expectations that upon beginning OEL care, they should be the main decision makers for the care plan, regardless of wishes of the dying and the medical advice supporting their decision. With the EOL patient going in and out of consciousness, the doctors in this case end up supporting the wishes of the daughters and administer care to their mother despite the DNR. As this treatment progressed it was clear to the doctors that they had made the wrong decision, which was later confirmed by the dying patient after she briefly regained consciousness and reiterated to her daughters her wishes for the DNR order. This situation presented a cautionary tale for medical professionals and family members alike to recognize the potential costs of conflictual care plans between dying persons and their family members.

Although there is much research on EOL care to lend clues to how actors in dying might set the expectations of familial caregiving, there is not an explicit account of (1) what caregivers expect their role to be when they begin caring for the dying and (2) what the external forces that shape how expectations of care become the tangible care they are. To address this shortcoming, I conducted interviews with 25 family caregivers of hospice recipients. Below I present the methods and results for addressing this gap.

Methods

A full description of the study methods can be found in chapter one. Below I present methods relevant to the current chapter in particular.

Data Analysis

Analysis is focused on respondents' stories of providing instrumental care as opposed to instances of emotional care my respondents also provided. Instrumental care provides a clear way to articulate the expectations of care because all care-receivers required some form of instrumental care. While emotional care at EOL is also a major component of the caregiving experience, there was variation in how respondents engaged in the emotional aspects of care. All of my respondents were able to articulate their experience of instrumental care which is the focus of the following study.

Respondents were asked many questions in the interview guide categories of “the care plan”, “family members as actors in the dying process”, and “dying”. Within these categories, answers to the following questions comprise the data for this chapter: How did your family decide between receiving care in the home versus in a facility?; Who has more bearing on what your care plan looks like, medical professionals, you, other family members, or your family member? Why is that so?; How has your experience matched up with what you expected of Hospice care?; Do you ever disagree with a part of the care plan? Why? How do you deal with this?

By considering responses to these questions in tandem, a new category of caregiver expectations was developed. After coding for this theme was complete, I coded for themes within and found caregiver expectations of “unbiased ally”, “deferential supporter”, and “unbewitting bystander” to be salient. Results from these distinct expectations of familial care are presented below.

Results

The results below illustrate how caregivers adopted distinct expectations of care from others. In describing the roles they played in administering instrumental care, family caregivers provide insight into the guiding forces that informed these care expectations. For *unbiased allies*, the care expectation they adopted was the result of a collaborative approach to caregiving. While for others, the care expectation was informed by forces that limited or excluded their desired involvement care activities or in care itself. Specifically, *deferential supporters* had ideas of a change they wanted in care plan, but either did not voice or push for their desired change to be adopted because of the decisive action of others. Similar to deferential supporters, *unbewitting bystanders* wanted to be involved in the care plan in particular ways but, unlike deferential supporters and unbiased allies, they were not allowed to be involved in aspects of care (or care as a whole) because of an outside guiding force (such as other family members close to the dying person). These distinct care role expectations are summarized in Table 2 and explored in further detail below.

Table 2. Description and Distribution of Care Archetypes

Care Archetypes	Key Characteristics	# of participants
Unbiased Ally	Unfettered collaboration guides this approach and as a result, conflictual care plans do not arise between respondent and other caregivers and/or the dying person.	9
Deferential Supporter	Respondent holds a clear and conflictual care desire but does not advocate for a care change in any meaningful way. Conflictual care desires may be verbalized or not. Respondent adopts the care plan of outside influences, usually from other key caregivers or from the dying person.	11
Unbewitting Bystander	Respondent desires increased involvement and agency in caregiving, but their involvement is censured. Outside guiding forces, typically from other key caregivers or the dying person severely limit caregiving attempts.	5

The unbiased ally

Unbiased allies adopted the care plans of forces outside themselves. Their orientation toward care was shaped by actively seeking *collaboration* with outside guiding forces, most frequently with the wishes of the hospice receiver themselves and other key caregivers.

Stefan was a college sophomore when his father was diagnosed with advanced stage prostate cancer and given a life expectancy of between 5 and 9 years. Upon this terminal diagnosis, Stefan and his father had a conversation about whether Stefan should move closer to home to care for his father. Stefan suggested moving closer to his father so the two could attend doctors' appointments together, not because that is what Stefan wished to do, but because he believed he should at least ask. Stefan's father quickly dismissed this as a viable option. There was no disagreement, likely because Stefan didn't believe in his proposed plan to begin with, and Stefan agreed with his father's decision readily:

> I was [living] two and half hours away from my dad. And we were like well should I transfer? No, we're both kind of like it's probably best if we just keep living our lives. And he didn't have a bucket list or anything. He's like I'm going to work here. He was actually lecturing [at the university…]. So everything was here. And so, I was like, "should I transfer?" And he was like no let's just continue on and […] the idea was to keep working as normal and everyone was fine with that. And I would be at [school], just going through college and everything. And so, it was an idea of normalcy.

Stefan offers to live closer to his father thinking that may be expected of him, an expectation his father quickly corrects and instead he guides the care plan toward "normalcy". Together, the two confirm the decision to limit Stefan's daily care. In this example, Stefan offers to move closer without any intention of following through if it is not also the wish of his father. Stefan quickly adopts his father's approach to Stefan's (limited) involvement in care.

Jenna took a similarly collaborative approach to caring for her ex-sister-in-law, Hannah. Upon getting diagnosed with advanced stage ovarian cancer, Hannah reached out for advice because Jenna's own sister died from the same disease years prior. Jenna views her role in the care team as a truly unbiased ally, but one that happens to have the wisdom of experience to offer. In addition to vising daily, feeding and taking physical care of her, Jenna readily talked with her ex-sister-in-law about her sister's experience. Jenna saw this aspect of her caregiving as providing care *information*, rather than care *directives* to Hannah. This seeming contradiction of unbiasedness and wisdom worth sharing created a dynamic where Jenna would offer her care contributions based on what was helpful for her sister, while genuinely viewing those contributions as optional:

> Jenna: While she was making those decisions, she asked certain things about my sister's experience and other peoples' experience and then sharing what she'd thought she was going to do—she was adamant what she was going to do. So she wasn't asking for [advice] necessarily—she just wanted the experience, but she was pretty adamant at what she was going to do. So I wasn't instrumental in her decision making.
> LGK: So, if you had a close friend, or somebody you knew was about to go through the experience that you went through, what advice would you give them?
> Jenna: Listen, listen, listen… Listen to them. Listen. And listen to yourself and be open—there is no set strategy, there's no set avenue, no direct route. Also, it's not just the cooking and meals, it's just sometimes literally being there and often times too, getting a sense of when to step away too.

In addition to giving instrumental care, Jenna collaborated on the care plan by providing the information that Hannah will use to make her *own* decision about her care. Despite her intimate knowledge of Hannah's prognosis and the regrets Jenna has harbored in how she cared for her sister, Jenna did not try to exert control over Hannah's care and holds no alternate ideas of what this care should look like. Jenna repeatedly stated that the role of a caregiver is to "listen" to the care receiver and "[get] a sense of when to step away" in addition to providing instrumental care such as cooking and meals. Here the care Jenna provided is wholly responsive to the wishes of others, namely her sister-in-law.

John was caring for his wife who was dying of stage 4 lung cancer, and he described her dying as: “gradual, and then it was upon us, and then it was over.” For gradual portion of her health decline, John noticed his wife losing weight without trying, her body weight eventually reaching less than 100 pounds, and declines in her energy levels causing her to stop doing her daily yoga. He described that these gradual changes were hard to recognize from day to day but were stark by the time she sought doctors to investigate what was happening. Once in the care of doctors, John’s wife’s decline was quick, and her moments of lucidity and consciousness became scarce.

When asked how he came to decide on home hospice over facility care, John states that by the time that decision was upon him, his wife was no longer able to voice her opinion: “She couldn’t make rational decisions. Or having a conversation with her—sometimes she’d be lucid and then sometimes it was like she wasn’t there.” Because of this, John relied on what he imagined her decision for the hospice setting would be: “I think she herself would rather have been home with her cats and flowers and hummingbirds and stuff than she would be at a strange facility.” Looking for confirmation that he is making the decision his wife would have wanted, John recalled a conversation with the doctor who treated her lung cancer and helped the family transition to hospice: “He was very reassuring and [saying] it’s probably the best route to go. They all try not to tell you what to do because of government [regulations]. But sometimes people need to be told what to do.”

Taken together, these quotes illustrate John’s commitment to carry out the care plan his wife would have wanted without letting her care be guided by the plan that *he* would want for her. Although John’s wife was not able to make the decision herself at the end of her life, John constructs a collaborative care approach by drawing on previous conversations with his wife and on the decision he *imagines* she would make. Further, John declared his personal divestment from directing the care plan by stating that “sometimes people need to be told what to do.” This leaves John totally open for the collaborative approach of unbiased allies whereby the direction of the care plan is determined by forces outside themselves, in his case from his wife (and with the doctor’s support).

Unbiased allies relied out outside messages to guide the role they played in caregiving, most frequently relying on messages from the dying person themselves. Further, unbiased allies’ overall approach to providing instrumental care did not involve their *personal* desires for what care should look like. Said differently, unbiased allies did not hold different opinions on or wishes for the care plan, instead they genuinely viewed the role of a caregiver to be unbiased and in total support of guiding forces outside of themselves. This approach stood in contrast to deferential supporters and unbewitting bystanders who had clear personal opinions of alternate care plans.

The deferential supporter

Deferential supporters desired a change to the care plan but did not articulate this in a meaningful way during the caregiving period. Deferential supporters either kept their alternate care ideas to themselves or softly suggested them to a member of the care team, but ultimately did not pursue their desired change to any consequence. Using the deferential support strategy, caregivers adopt the expectations of care set by others, despite their own ideas for an alternate plan. The control exerted by outside guiding forces was heeded by the deferential supporter, and the expectation of supportive deference was thusly established and reinforced. Outside guiding forces included the dying person themselves, another familial caregiver, and/or members of the medical community.

Tony's father, a military veteran, was diagnosed with non-Hodgkin's skin cancer suspected to be the result of exposure to Agent Orange after serving several tours in Vietnam in his youth. Tony and his father had a complicated relationship and Tony often spoke of his simultaneous distain and respect for his father, noting that they had gone through periods of estrangement beginning in Tony's teenage years. The two began talking again after Tony's sisters called to let him know that their father was unwell, and Tony soon learned that his father placed explicit limitations on the kind of care he would accept from family and medical professionals alike. After his cancer diagnosis, Tony's father entered treatment for one week before deciding to forgo treatment and enter into hospice. Tony recounted learning of his decision:

> LGK: Did you ever have conversations about, hey this is the end of the line?
>
> Tony: No. I mean it was more like a— so, you're sure? I'm like you seem to do really good from that [treatment], so you're sure you're not doing anything else? And it was more just open ended, like seriously. And he's like, "no." I'm just like— "that's why I'm here" and he's like "okay if we keep talking, we're going to be arguing". I'm like fine, whatever. Again, it wasn't productive to argue with him. At that point he might tell me to get out of there then and not want me to come back. So, I was like, if for no other reasons, some of it was I'm not going to have you die like this and feel like I didn't at least try to be there for you. Like regardless of how we were, that will help me live with it better".

Tony quicky realized that in order to stay involved in his father's care, in whatever limited capacity he will allow, Tony had to accept his father's care decision without objection. Tony indicated a clear understanding of what he would like his father's care to look like, i.e., continuing treatment that seemed to be working. He softly voiced his dissenting opinion on the care plan by asking "are you sure?" and is rebuked by his father. Tony's dissenting opinion even caused him to question the ethics of his father's medical staff, saying: "my conversations with the medical staff [were] that I just didn't understand how that was ethically okay [to let him discontinue treatment]. Like, don't you guys take the Hippocratic oath and all that? Like you have to treat him." However, Tony's vision of an alternate care plan was quickly censured by his father and Tony just as quickly fell in line:

> "I didn't want to argue with him at the end […]. It was like well things are as they are: I'm your son, you're my dad, you're dying so I can at least try to be here. And being as good as I could to not [cause trouble]— why cause trouble? He's already going to die so I'm like what good is that going to do? So, we didn't talk too much about that."

The situation of Tony and his father illustrates how deferential supporters have clearly thought-out opinions for a care plan that differs from another member of the care team, in this case from Tony's father himself. Despite this, Tony adopted the role of deferential supporter and did not voice his opinion to any consequence. Instead, Tony opted to go along with his father's wishes, seeing this as the only way he can remain a member of the caregiving team. Further, Tony noted an emotional benefit of adopting the deferential supporter role— deferring now allowed him to remain on the caregiving team, even if in a limited capacity, which “will help [him] live with it better” after his father dies.

Michaela’s father suffered his first heart attack when Michaela was only 29 years old and for the next decade his health continued to decline slowly. Aside from high blood pressure, high cholesterol, and diabetes, he had congestive heart failure and eventually developed lung cancer. At the intersection of these comorbidities, Michaela’s father’s doctors recommended hospice care. In her father’s final days, Michaela’s mother became gravely ill following a surgical complication that sent her to the hospital while she was visiting one of her daughters who lived in a southern state. Michaela described how her mother directed Michaela’s father’s care from her own hospital bed:

> “Michaela: But when my mom came to after surgery, we told her that my dad was getting worse and that he was. [The doctors] had told us that things were likely to progress pretty quickly. And so, she went immediately into her mom mode. There wasn't a tear shed or anything. She said, "Okay girls, go down in the basement, on the shelf in the basement on the right-hand side there's a box. The key to the box is here. Here's all the documents you need for everything." And we were... I remember going, "Oh my gosh. This woman has everything planned out, everything. Down to the last detail. He ended up dying a couple of days later.”

Above, Michaela described being surprised at her mother’s ability to direct the care plan from a different state and while recovering from a major surgery. Her mother directed Michaela to retrieve documents that exhaustively outlined the care decisions Michaela and her sisters were to use as they provided care to their father in his final days. Her mother’s control over the care plan, in spite of Michaela and her sister’s alternative plans, further manifested in the planning of the funeral:

> “Michaela: She was still in the hospital and wasn't able to travel home for about two weeks later. And she insisted that we go on and have the funeral without her. We wanted to wait at least...

> LGK: How did that feel for you?
>
> Michaela: It was really weird. It was awkward. We all talked about like, "Should we just wait and just do something when she comes back?" But she didn't want to, she wanted us to proceed and not to wait, and she... Yeah, it was... Yeah, that was weird. I remember it being, being very awkward. And of course, everybody at the funeral [and at the calling hours 19:08] were asking. […] But she did, she had everything planned out. She told us exactly who to call, what to do, how to do it. So, we didn't... You asked earlier if we had conversations and we talked about it? She told us what to do and we did what she told us to do […].
>
> LGK: Is that your ideal way that that would have gone down?
>
> Michaela: I think that ideally, I would have done it differently."

Through the language she used to describe the situation, calling her mother's actions "awkward" and "weird", Michaela began to indicate that her wishes for the care plan were different than what her mother had outlined and pushed for ("Ideally, I would have done it differently."). Michaela further asserted her differing wishes for the care plan as she recounted having conversations with her sisters about possibly directing care themselves (We all talked about like, "Should we just wait?..."). However, these conversations never resulted in a change in the care plan that their mother outlined with Michaela saying, "She told us what to do and we did what she told us to do." Together, these examples illustrate the hallmark of a deferential supporter approach to caregiving as one where a clear alternative to care is identified and desired yet does not come to fruition because of a lack of *asserting* this desired change.

Catherine and her family displayed a similar devotion to deference of the hospice recipient as they coordinated end-of-life care for her father. Catherine's father had dementia that got progressively worse, saying: "He and my mom were both retired. They just did stuff together and then it got harder and harder for them to go places […] and it got to the point where she couldn't comfortably go and do errands without worrying about him being at home. It was hard for him to get in and out of the car […]. He was super healthy and then he just had a stroke, and that kind of exacerbated it." This decline led the family to pursue hired help to look after Catherine's father's needs at all times:

> "So, last summer somebody my mom volunteered with said, "Oh, I know somebody who can maybe come and help you." And that's how they got somebody in there. At first, my dad really hated it. He didn't want anybody there. He said, "I don't need a babysitter, I'm totally fine." At that point he didn't really realize that he wasn't fine. So, we kind of drew up a document that we signed saying that mom needs help and that she needs somebody to help her do laundry and get groceries and so we all signed it, that it was okay for that person to stay there […] we said, okay, we'll give it a month."

Catherine and her family identified her father's need for formal care early on. Anticipating that her father would disagree with this care intervention, the family devised a plan that increased his level of care gradually ("we'll give it a month") and under the guise that the help was for Catherine's mother. By leveraging the idea of Catherine's mother needing help as the basis of initiating care, the family left Catherine's father to decide if he would accept care to supposedly aid his wife, which he did. Once the care was hired, the family made sure that any escalation in care was seemingly Catherine's father's idea first: "So, she [the hired help] stayed because he got used to her." Here, Catherine described an iterative process of negotiating her father's care where *creating* deference to his willingness to receive care at every step was key. Through writing a 'family' contract, and surreptitiously involving hired help in her father's care, the family demonstrated great commitment to creating an air of deferential support in caring for Catherine's dying father.

Deferential supporters highlight the sacredness of the dying role. The care wishes of the dying are supreme and untouchable, even when family members have clear ideas of how they would like to see care executed in order to best support themselves and their loved one. Most deferential supporters simply comply with the wishes of the dying person and at least one of my respondents was so committed deferential supporter role that they manufactured a context of deference.

The unbewitting bystander

In contrast to deferential supporters who were allowed to administer care, albeit not in the way they would have liked, unbewitting bystanders wanted to offer extensive care, attempted to administer care on multiple occasions, but their involvement was *severely* limited by guiding forces outside of themselves. In the face of these severe care limiting forces, unbewitting bystanders were not privy to the decision making that cut them out of the caregiving role they envisioned.

Rae's Auntie was the central mother-figure in her life and Rae invested great time and energy into maintaining a close relationship with her. Rae was shocked to learn of her Auntie's involvement in hospice only two weeks before her death despite her Auntie being in hospice care for several months. Even with such little notice, Rae attempted to jump directly into care for her Auntie. She repeatedly asked her Auntie and her Auntie's children if she could be involved in administering care, but Rae was only able to get away with participating in the occasional appointment drop-off or washing of dishes, saying of her attempts "'Auntie, are you feeling better? Auntie, is there something I can get you? Auntie, now please let me help you'. She was the kind of person that would reach out and help anybody but wouldn't accept help. So, I would go over and see the dishes, which was unusual, and do the dishes.” Rae displays a knowledge of the care limitations placed on her by outside guiding forces. These limitations force her to administer care in surreptitious ways, such as quickly doing the dishes when she sees them, even though she is not supposed to be contributing to care in this way.

Rae was even forbidden from contributing financially to her Auntie’s care. As a result, most of Rae’s care involved emotional support because she was cut off from more tangible forms of care. When asked why she thought she wasn’t allowed to be involved in Auntie’s care as much as she would have wanted Rae says, “So I think that in-between […] my different transitions in life, and then me being a big selfish mouth and telling [Auntie] my problems and wanting her input, I think for all of those reasons is why my money was refused, the same reason she didn’t want them to tell me, she didn’t want me to worry. Or to be unhappy. Maybe she didn’t want me to change, I don’t know. I just wish she would have told me. I wish they would have told me earlier, sooner”. Rae can only guess as to why she was excluded from caring for her Auntie in the way that she wanted to. All of her attempts were denied and now five years after her Auntie’s death Rae is left with an overwhelming sadness at not being allowed to offer care.

Lena was slated to begin graduate school across the country from her family when her mother became terminally ill with cancer. She describes an extraordinarily close relationship with her mother and the two made as many memories together as possible before her mother’s death, such as picking out Lena’s future wedding dress even though Lena was not dating. Prior to starting school Lena was involved in caring for her mother, particularly in administering her pain medication, but that changed dramatically as her moving date approached. Lena explained how her father pushed her out of the house and out of the care team when it was time for her to start grad school:

> "Everyone was like '[you leaving] is what your mom would've wanted'. She never said that to me, so I was like is this what my mom wants from me or is this just what people are telling me. And my dad was like "no, honestly you've done your part and I think that I wanted to take care of her, and your sister is here too so you can just go". So, I came [to graduate school] and I was like okay. And in those two weeks… It was so long. I was like by myself in this empty apartment with no furniture because it hadn't come yet and I didn't know anyone. So, I was like [trying to] distract myself. And so, I didn't want to come home and like, I call her my aunt— one of my mom's best friends was like 'honey you can come home if you want to'. And I was like honestly, I think I'm going to stress out my dad more. I helped him to the degree that I can but again he was like 'I have to do this, or this is what mom wants.'"

Because of the mystery surrounding her dad's decision to cut her care contributions short ("is this what my mom wants from me or is this just what people are telling me?"), Lena had a very difficult time accepting that she was not able to be there in the final moments of her mother's life. As a result, Lena experienced intense and protracted grief she described throughout her interview. Lena attempted to placate her decision to defer to her dad's wishes by saying "I have to do this, or this is what mom wants," highlighting the lack of agency she had in being involved in the care plan in the way that she wanted to.

Benjamin was charged with caring for his aunt who was dying of dementia. While lucid, Benjamin's aunt drafted strict care directives for Benjamin that allowed him full latitude to care for her physical and financial health in the way he saw fit but forbade his ability to seek advice on how to make those care decisions. Concretely, per her will Benjamin could not disclose her health or financial status to anyone until after her death.

Throughout the caregiving process, Benjamin was reflective on whether or not the care decisions he was making were the "correct" ones, particularly decisions related management of the properties she owned and her diet:

> "Benjamin: "I couldn't tell [my siblings] how much money she had. I couldn't tell like all the properties she owns, where they were located. So, I had to keep that to myself. I had to keep these things to myself until she passed away. Then I could say, you know, her preferences were to do this and that and that with the property and that sort of...
>
> LGK: What did that feel like to learn that this was a stipulation?
>
> Benjamin: Very lonely
>
> LGK: Oh, say more about that.
>
> Benjamin: Yeah, so I felt like, like I was not being truthful [to my siblings]. And I didn't Like that. I didn't like the fact that I couldn't really say.
>
> LGK: When you wanted to talk to family members about things that were going on in her health, what was lost by not being able to access those opinions?
>
> Benjamin: Because when you think about care, you just want to use whatever. You're reaching for all of those different aspects. So, they may need vitamin D, but you didn't explore that. While talking to another family member about benefits of vitamin D because they got some information maybe from Europe that's really brilliant at the time. And then you're using that to take care of your patient, that to me is valuable and I would've wanted to know that.
>
> LGK: So, did your family know there was this non-disclosure clause? Were they ever wondering 'how come we don't know more about this'?
>
> Benjamin: Yes, yes. And I did say that, and I said she has a very tightly detailed will that doesn't permit things to be spoken about, and that was her wish. So, then I was like 'Okay, I'll shut up.'"

While providing care for his aunt, Benjamin described multiple occasions of wanting input from others to make sure he was doing the best job he could to care for her. This ranged from the how to best get her financial affairs in order to the vitamins she should be consuming. Benjamin could come up with no explanation for the restrictions except perhaps his aunt’s meticulous nature, saying of the decision to limit the help Benjamin could seek: “I think was a part of her personality. I think it has a lot to do with her work. Because as a as a surgical tech, she knew all the surgeries. So basically, she was a surgeon.” Benjamin referenced the possibility of his aunt’s meticulous nature and heightened sense of control in her profession that was translated into how she outlined her care at end-of-life. His aunt’s strict control of her care limited Benjamin’s ability to care for her in the way he wanted because he was not able to seek the opinions of others. Further, the reasoning behind his aunt’s explicit limiting of Benjamin’s ability to care for her in the way he wanted was a mystery. It is this unique combination of restricted care possibilities and lack of knowledge as to why the restrictions exist that characterize the experience of unbewitting bystanders.

Discussion

Hospice care entails a transition from medical care to familial care, and how family caregivers navigate this seismic shift is not fully understood. Failing to investigate this limits our ability to understand issues of agency in care in the ever-relevant context of EOL. Interviews with 25 family caregivers of persons in hospice revealed both what caregivers expected their role to be in caring for a dying family member, as well as how these expectations shaped the care they actually provided. Their stories yielded distinct care approach archetypes including the unbiased ally, the deferential supporter, and the unbewitting bystander. Further, experiences of family caregivers highlight that approaches to care of the dying are determined by guiding forces that exist outside of the caregiver themselves.

Some familial caregivers of the dying adopted an unbiased ally approach, whereby the plan they developed, and its associated care was a collaborative endeavor, working closely with the dying person themselves and other key familial caregivers. Unlike other approaches, unbiased allies do not enter the care context with a plan in mind and when a care conflict arose, unbiased allies easily pivoted in achieve harmonious care plan. Because of the focus on collaboration, care receivers quickly accept the direction of outside guiding forces and, importantly, without internalizing a care conflict's implications. In contrast, conflictual care plans were a prominent guiding force in the remaining caregiving approaches.

Deferential supporters desired to change the care plan, were privy to the opposition's reasoning behind the conflict, and ultimately chose to silence their wishes to remain a part of the care team. The silence of deferential supporters indicated that they saw their ultimate role as serving the wishes of the dying even when they thought they could administer better care by changing the plan. Unbewitting bystanders experienced the most extreme censures to their care efforts with many being fully blocked from giving care and unique to this group was the mystery surrounding the decision making that limited their ability to care for their family member. The mysterious nature of care planning likely exacerbated feelings of lack of agency in caregiving among this group. These findings imply that distinct strategies to caregiving do exist, that the shape they take is most heavily determined by forces outside of caregivers themselves, and that this holds implications for (limited) agency in familial care of the dying.

In many ways, finding that distinct familial care approaches exist in EOL care is unsurprising. Hospice represents a context of transitioning care away from formal medical care, and toward greater inclusion of familial care (Hudson & Payne 2011). At EOL medical professionals act in ways that confer the ultimate caregiving trajectory on family members, and this is often true regardless of whether the dying person has an articulated plan that is different than the family's plan (Abadir et al. 2011). Additionally, burgeoning research on the types of information medical professionals provide to family demonstrates that family caregivers received targeted instruction and support to care for their loved one whether care is administered in the home or in a facility. Namely, family caregivers of persons in home hospice tend to receive more instruction on instrumental care tasks, while family caregivers in institutionalized settings tend to get more information on financial considerations (Lavalley 2018). Thus, what is created is a context where family members presumably *must* develop *some* strategy to navigate this new role without the heavy guidance of medical professionals. The current study goes beyond providing empirical evidence that familial care approaches exist, to explicating the variation that exists in these approaches.

Finding that conflictual care plans arise at EOL is perhaps also predictable, as much research alludes to the differing desires of family and dying persons regarding care giving and receiving. The dying set expectations that limit the involvement of family care for fear of becoming a care burden (McPherson, Wilson, & Murray, 2007), and the desire to avoid burdening family is deeply connected to decreases in autonomy and independence that occur during the dying process (McPherson, Wilson, & Murray, 2007). At the same time, previous research indicates that family members see themselves as responsible for main caregiving tasks and decision making (Hudson & Payne 2011). For example, in cases of instrumental care family is also seen as able to effectively perform the emotional labor to cater care to the receiver in ways that might increase their feelings of respect and integrity (Isaksen 2002). However, *how* conflictual care plan ideas influence *actual* care has not been empirically established until the present study. I find that conflictual care plans, or the roots of conflict, are present in all care approaches in ways that guide how care itself is carried out.

The surprising element of my findings comes not in the mere existence of care approaches generally, or even in describing the forces that guide a particular approach, but in the implications both have for caregiver agency at EOL. Before hospice, caregiving is the primary task of medical professionals, who confer this great responsibility onto family members at hospice initiation. While great responsibility is transferred, a corresponding power over care does not. Note that my results do *not* indicate the existence of a familial care approach where meaningful agency of a familial caregiver occurs: unbiased allies care at the whim of genuine collaboration directed by forces outside of the ally, deferential supporters envision a more effective route to care but abandon their desires, and unbewitting bystanders' care offerings are rendered useless (either in part or in whole) by guiding forces existing outside of themselves. Very little seems under the direct control of the family caregiver for a person in hospice.

The findings of this three-fold typology highlight how the externally defined expectations of hospice caregiving compromises the caregiver's agentic power. Given that much of sociology is centered on identifying social disenfranchisement to eliminate it, the present research establishes EOL caregiving as a new context in which to understand inequality as it relates to individual agency. Future research should establish the concrete benefits or consequences of limited caregiver agency in matters of EOL. It is possible that the emotional and mental health consequences of losing a loved one are further compounded by the limited agency felt by caregivers of the dying and these potentially compounding effects should be studied in future research. Only by understanding the full scope of emotional and mental consequences of caregiving can we begin to offer adequate support to caregivers both during the time of caregiving and after the death has occurred. It is also possible that limiting agency is part of a social exchange one makes for some other outcome that is more beneficial to the caregiver than individual agency might be. If future research finds this to be true, it stands to fundamentally alter our understanding of individual agency as something to be supremely desired.

Chapter 3. Correcting Care: How Families Subtly Navigate Differences in Hospice Caregiving

Introduction

Upon initiation of hospice or end-of-life (EOL) care, families become the primary caregivers of a dying loved one. Despite this monumental shift in care responsibility, surprisingly little is known about how families negotiate care with other caregiving actors, particularly when caregivers must contend with a care act they deem as improper or inadequate. A key part of caregiving during hospice is *care correcting,* or efforts to alter the caregiving act or intention of another actor in pursuit of "proper" care (for example, see Abadir et al. 2011). Looking to an expansive body of research on patienthood and care negotiations between doctors and their patients, as well as negotiations between family members when one member requires treatment, demonstrates the pervasive occurrence of care corrections launched from one care actor to another (Reczek et al. 2018; Reczek et al. 2020; Timmermans 2020). Among these care corrections, a subtle (defined as indirect, such as implicit illusions to a *possible* care change or awareness of an alternative treatment option not applied to the current situation) approach to correction is most common while overt (defined as direct, such as explicit statements of a desired care change to a doctor with the power to make said change) correction is rare (Stivers, 2002).

Prevailing understandings of care correction use samples of parents advocating for their children's medical treatment and show that subtle care correction of medical professionals occurs frequently (Gengler 2015; Stivers 2002). Subtle correction in these contexts takes the form of stating a general awareness of an alternative care option without directly asking if that treatment can be applied to the patient, for example (Stivers 2002). Additionally, studies on how spouses encourage their partner to seek physical and mental health care reveal the prevalence of subtle approaches aimed at altering how one spouse interacts with formal medicine. For example, spouses use destigmatization of mental health generally to encourage a loved one to seek care for their specific mental health concern (Reczek et al. 2020). Despite their contributions to our understanding of subtle corrections in health care interactions, these studies are limited by their focus on early- and mid- life. Additionally, although research on advanced care directives, power of attorney, and elder abuse suggest fertile ground for care corrections to occur, missing is an account of the most prevalent form of correction—subtle correction— as manifests in the context of EOL care.

Further, prevailing theories on the motivations behind care correcting rely almost exclusively on the explanatory power of whether patients possess the Cultural Health Capital (CHC), or "the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interactional styles, cultivated by patients and clinicians alike" (Shim, 2010), to leverage in a care interaction or not. Together, this focus on care correction in the context of parenthood and midlife spouses, along with sociology's preoccupation with CHC, has stifled our ability to discover new motivations that might undergird a subtle approach to care correcting. Given the prevalence of subtle correction in the contexts of doctor-parent interactions and among midlife spouses, it reasonable to expect that subtle care correction occurs in the context of EOL care. However, virtually nothing is known about whether subtle care corrections occur in the context of hospice care specifically, and what motivates a subtle approach. Moreover, virtually no research exists on whether subtle correction *between* family caregivers occurs during EOL care (Ward Griffin, Mcwilliam, and Oudshoorn 2012). This dearth of knowledge is alarming, particularly as it relates to our understanding of hospice care experiences where professional medical involvement diminishes in favor of family members who become primary caregivers.

To establish the relevance of subtle care correcting in familial hospice care, this study focuses on enactment of the most prevalent form of corrective action in other care contexts—subtle correction. The aims of this effort are two-fold: to determine whether subtle care correcting occurs in the context of hospice care by asking (1) who family caregivers of someone in hospice subtly correct? And (2) what motivates a subtle approach to care correction? Answering these questions gives insight into complex care processes that occur in the ubiquitous context of care for the dying. Understanding subtle corrections familial caregivers leverage when confronted with improper caregiving reveals decision making processes at the intersection of care infractions and constrained caregiver agency.

Background

At present, care corrections are understood through the lenses of doctor-patient interactions and spousal relationship dynamics. These studies reveal care correcting behaviors without the using the terminology of care corrections explicitly. Thus, for the purposes of the present study, care corrections are defined as efforts to alter the caregiving act or intention of another actor in pursuit of “proper” care. Understanding care correcting theory must begin with an understanding of patienthood as informed by the changing landscape of the doctor-patient relationship and the care negotiations therein. From this foundation, I layer on an overview of current theorizing of care corrections that is focused on (and limited by) a preoccupation with the explanatory power of CHC to understand motivations behind subtle correcting behavior. I follow this detailing of current theory with a brief overview of how more contemporary work is combining and innovating these theoretical applications anew to advance the burgeoning field of care corrections research. Finally, I provide empirical examples of *between* family care negotiations as they occur among married spouses who encourage their partner to seek physical and mental health treatment. Although these studies do not tell of families negotiating care at end of life, they illustrate the existence of *between* family care corrections and suggest their possible relevance to the present study.

Theorizing Patienthood

By juxtaposing the roles of and interactions between patients and their providers, and the changing expectations of patienthood, patienthood itself can be defined. Chronicling the evolution of the doctor-patient relationship reveals an ever-evolving care dynamic. Beginning with the consolidation of power within the medical profession in the late 19th century, such as through establishment of the American Medical Association, the top-down (i.e., doctor to patient) medical model was established (Halfmann 2011; Starr 1984). Thus, full medical authority and power was placed squarely in the hands of doctors (Starr, 1984; Foucault, 1963). However, technological and social advances have spurred changes in this dynamic with a more patient-centered model becoming the desired standard at present-time. Most notably, technological advances such as the internet have greatly altered the terrain of medicalization as it is exercised by both patients and doctors.

With the evolving doctor-patient dynamic there has been a corresponding evolution in popular conceptions of patients over time (Timmermans 2020). These conceptions include the expert patient which signals the equalizing of medical authority between patients and doctors (Fox and Ward 2006) and the empowered patient which appeals to modern day social and legal ideals (Andreassen and Trondsen 2010). On the cutting edge of conceptualizing the modern patient, Timmermans (2020) argues for the language of the “engaged patient.” This terminology connotes both a patient’s active *involvement in* health care interactions and the *responsibility to* be actively involved in the care processes applied to them. This conceptualization also directs attention the latest iteration of the patient-doctor relationship that is characterized by care *negotiations* rather than the directives of past top-down dynamics (Timmermans 2020).

There is great diversity in how this historically new patient-doctor care dynamic is navigated. For doctors’ part, there is evidence of a bivalent approach to care interactions, particularly when delivering bad news (Stivers and Timmermans 2017). Bivalence in this context refers to a simultaneous presentation of good and bad elements within the care conversation. A bivalent approach serves as an attempt to establish or maintain effective rapport between doctors and their patients in order to make inevitable care negotiations as productive as possible (Stivers and Timmermans 2017). For patients' part, strategies such as using "topicalized small talk" with doctors (or discussion of mundane and neutral topics) is used to increase a sense of intimacy that then allows patients to feel more comfortable launching complaints with their doctor (Hudak and Maynard 2011). Taken together, the evolution of doctor-patient expectations and interactions and the care negotiations therein illustrates from all perspectives that to engage in a caregiving relationship is to engage in care correction.

In medicine, a patient is typically imagined as the singular person receiving or consuming care, often for an illness that requires formal medical attention. However, at EOL and in the context of hospice in particular, this narrow notion of patienthood is challenged as trusted others (frequently family) must increasingly serve as patient proxies when the care recipient cannot make independent care decisions. Because of this, some scholars have conceptualized of *the family* as the patient in hospice care (Thomas et al. 2002). Thus, in the context of hospice care, family members occupy the dual role of patient and care provider. Said differently, at EOL we move away from medical professionals and patients being the interactional actors of interest. At EOL interactions *between* family members become the unit of observation where care corrections occur. The heightened importance of between family care negotiations at EOL is highlighted in research on how families navigate advanced care planning directives. This is seen most notably in research on familial exploitation of the powers of attorney rights (POA) where exercising those rights risks financial exploitation of the elder patient being cared for. Among these occurrences of financial exploitation, family dynamics can signal precursors of abuse (Steinman et al 2020). Specifically, family dynamics of perceived fairness, entitlement attitudes, resource exchange patterns, and communication/problem-solving are differentially associated with financial exploitation when one family member assumes a POA role (Steinman et al. 2020). Regardless of the combination of family dynamics that precede abuse, guardianship of this type is associated with increased disagreement among family about how care should be executed (Wood 2018).

Theorizing Care Corrections

Prevailing understanding of care corrections outlines two distinct dimensions of care correcting. First, one strand of theory explores the *occurrence* of care correction (i.e., care correction either happens or it does not). A second theoretical strand outlines the manner in which a correction is undertaken, categorizing corrections as either subtle (implicit) or overt (explicit) *within* instances where a correction *does* occur. Both of these theoretical orientations are born of studies on how parents advocate (or not) for proper medical treatment for their young children. To succinctly describe these unique, but compatible, theoretical orientations I first provide detail on Gengler’s (2015) study on parents of seriously ill children and it’s use of cultural health capital as an exemplar of care correcting research. I then turn to Stiver’s (2002) study on parents' requests for antibiotic treatment for their children to introduce more nuanced theories of doctor/patient interactions as they map onto care correcting.

Gengler's (2015) research on care provided to seriously ill children illustrates the *occurrence* of care correction well and uses cultural health capital to theorize why care corrections do or do not happen among her. Gengler shows that a family member's possession of CHC influenced their ability to understand medical results, care instructions, explanations of procedures, care plans, and anticipated treatment options. In turn, possessing an adequate level of CHC allowed some parents to request alternative treatments, evaluate the anticipated efficacy of a treatment plan, and be generally more engaged in the care of their child. Having CHC represented a micro advantage for parents, but not everyone possessed CHC at comparable levels. Parents without adequate CHC relied on the "expert" opinions of medical professionals more often and readily and indicated frustration at not feeling "heard" in their interactions with medical professionals (Gengler, 2015). This dichotomy of possessing CHC or not resulted in two groups of parents, one of parents who were able to "care captain" their child's treatment, and another of parents who were rendered "care entrusters". Gengler's example of parents caring for seriously ill children is illustrative of the dominance of CHC theory in care correcting research. Said differently, research on care correcting rests heavily on the explanatory power of CHC possession (or not) to describe differences between who exerts control over the care context or and who does not.

Burgeoning research in the field has begun to refine our understanding of how CHC is leveraged by drawing connections between CHC theory and the Fundamental Cause Hypothesis (FCH). Link and Phelan's (2010) FCH establishes socioeconomic statue as a major determinant of health because of its association with multiple disease outcomes, through multiple mechanisms. These multiple mechanisms are described by some as “flexible resources” such as “money, knowledge, power, influence, interpersonal resources, social support, and social net- works” thus positioning CHC as the lens through which resource mobilization *and* the associated rewards should be viewed (Gage-Bouchard 2017). From this conceptualization, Gage-Bouchard (2017) vividly outlined the different ways that parents leverage CHC/flexible resources to care for their children namely through vigilant, trusting, and antagonistic advocacy. This research added nuance to Gengler’s findings by outlining how parents’ self-presentation and interactions styles were used alongside leveraging cultural knowledge to exert control over their child’s care. Further studies on the role family members have in control over medical care have begun to move away from dichotomous conceptualizing of exerting control or not, to describe a “range of corrections” that are used (Lindstrom and Weatherall 2015). Conceptualizations of this type are highly nuanced and rare, indicating that the developing field of care corrections is fertile ground for further inquiry.

Moving beyond *whether* patient control is exerted in the care context or not, various theories illustrate the myriad of *ways* that patients exert control in the care context, most notably through a conceptualization of subtle or overt tactics. Illustrative of this theoretical orientation is Stivers (2002) study using conversation analysis of how parents care correct in pursuit of antibiotic treatment for their children. Specifically, Stivers found that parents used four primary strategies to assert their wishes for antibiotic prescriptions and that these strategies could be categorized as either overt (explicit) or subtle (implicit), defined by whether or not the approach required a response from the doctor. Overt (or explicit) strategies included direct requests or a stated desire for antibiotic treatment. Subtle (or implicit) strategies included inquiries about antibiotic treatment generally and mentioning previous experience with antibiotic use. Although half of the strategy types were overt, using an overt strategy was extraordinarily rare. The exclusive use of a subtle tactics to care correct is present in research on EOL decision making. Regarding the transition into hospice care, doctors' recommendations for a move from palliative to hospice care are frequently met with family members resisting the care shift (Spencer, Mrig, and Talaie 2020). Despite clear resistance, in care negotiations of this type families of the terminally ill tend to offer only a "soft no" where a transition to hospice care is "neither accepted nor overtly refused" (Spencer, Mrig, and Talaie 2020). Further, overt refusal of a transition to hospice care rarely occurrs.

Care correcting between family members

While examining the care dynamics between doctors and patients is essential to understanding most care seeking and receiving negotiations, care correcting in hospice requires additional analysis of care negotiations *between family members* charged with caregiving. Unfortunately, while doctor/patient care negotiations in general and at end of life specifically has been well explored, virtually no research on care interactions from familial caregiver to familial caregiver at EOL exists. However, research on how spouses correct the inadequate health care engagement practices of their spouse lends insight into corrective care practices *between* family members. Although this research is disconnected from the context of familial caregiving at EOL, it establishes the basic care dynamic of one family member attempting to exert control over how another family member engages in care using techniques with differing levels of severity.

Regarding physical health care, Reczek et al. (2018) use the language of *healthcare work* to describe efforts undertaken to facilitate spousal engagement with formal medicine. Using a sample of gay, lesbian, and heterosexual married couples the authors demonstrate that spouses use both supportive and coercive tactics to facilitate engagement with formal medicine for health issues in need of attention. Specifically, among all couple types, coercive techniques such as naming a spouse's reluctance to seek proper care as personally distressing were used to increase engagement with formal medical care. In addition to coercive techniques, same-sex couples frequently used a collaborative approach to enact healthcare work through mutual appointment making, attending appointments together, informally counseling a spouse on healthcare seeking concerns, etc.

Still without using the language of correction, Reczek et. al. (2020) add helpful nuance to the techniques one family member uses to correct another family member's deficit in mental health care. Again using a sample of married couples, the authors outline what could be conceptualized anew as subtle corrective approaches to addressing a care deficit. For example, reframing mental health problems as result of biochemical makeup rather than a matter of personal health identity (thus destigmatizing the issue) was commonly used by one spouse to encourage another to engage with formal medicine. An additional strategy found among lesbian spouses was one of introducing conversations of how mental health symptoms might factor into relationship quality of the couple. Finally, in the heterosexual context spouses used avoidant strategies whereby they were aware of a mental health concern in need of attention, but ultimately viewed care seeking as the responsibility of the individual and thus did not meaningfully involve themselves in healthcare work of this type. This research shows that upon noticing a care impropriety (i.e. not adequately addressing a mental health concern) spouse-to-spouse correction occurs with varying levels of intensity, often with efforts to soften the approach, and through diverse means. Further, a spouses care correcting behavior was motivated by either improving the health of their partner and the successful functioning of the partnership, or some combination thereof.

In sum, tracking the evolution of patienthood from passive recipient of treatment to engaged patienthood that entails not only an involvement in but a responsibility to active involvement in care processes lends credence to the exaggerated responsibility familial caregivers of the dying experience upon initiation of their caregiving duties. This call to command the caregiving experience is present in research on parents who advocate for proper medical treatment of their minor children. Studies of this kind outline whether familial caregivers correct care at all and that among care corrections that do occur, a subtle approach is most common. These prevailing studies on care correction rely on the explanatory power of CHC in why care corrections take on the various forms they do in the context of doctor-patient interactions. Borrowing from research on spouses encouraging each other to seek formal medical treatment suggests that care corrections also occur *between* family members. However, an exhaustive account of care correcting during EOL does not currently exist. Yet to be discovered in the context of hospice care is whether subtle care correction occurs, and if it does, what motivates it.

Methods

A full description of the study methods can be found in the introduction to the dissertation. Below I present methods relevant to the current chapter specifically.

Data Analysis

All data represent instances of subtle care correction respondents used to address improper care that was being administered to their dying loved one. In the current study, subtle correction refers to any attempt to alter a caregiving act performed by another caregiver where the corrective approach was *intentionally* limited and/or to no consequence (i.e. the limited approach did not lead to a change in the care plan). Respondents aimed subtle correction at both medical professional and familial caregivers. All instances of improper caregiving were related to activities of instrumental care, defined as efforts to contribute to the execution of activities of daily living that are "designed to meet the most basic needs of life" (Bernhold, Dunbar and Giles 2021). These efforts include bodily care such as medication administration, feeding, hygiene care or help with household chores such as shopping or laundry that contribute to successful activities of daily living of the care recipient (Bernhold, Dunbar, and Giles 2021).

Respondents' recounted instances of subtle correction as they talked about how care plans were put into action. Interview guide questions that elicited these accounts include: Were you happy with the care plan? What did you wish to change?; How did the care plan change over time? Do you think those changes were good?; Is there anyone you wish was more involved in the care plan? Less?; Asked about family and medical professionals separately: What sorts of concerns do you turn to [medical professionals/family] for?; Is there any information you keep/refrain from telling [medical professionals/family]? Why? What would happen if you told them this information? In responding to these questions, respondents revealed using a subtle approach to correcting what they viewed as improper care of their loved one. Subtle care corrections were given to both medical professionals and other familial caregivers. Given distinct relational dynamics between respondents and (1) medical professionals and (2) the other familial caregivers they interacted with (i.e. differences of medical authority and family history respectively), analyses of subtle corrections are presented accordingly. In all cases, a subtle approach to correction was motivated by some consideration related to family. Nuances in how family considerations were used is explored further below.

Results

The findings below establish that subtle correcting of the caregiving efforts of another person do occur in the context of care for the dying, namely through corrections aimed at medical professionals and other key familial caregivers. Subtle correction is defined as any modifying effort that was *intentionally* limited and/or not pursued in a way that produced any change in the care plan, most commonly by not directly addressing the person performing an infraction *or* the improper caregiving action itself. Subtle corrections were undertaken as an effort to improve the quality of care their loved one could receive. All results reflect caregiving infractions that occurred in relation to instrumental care (or care related to activities of daily living) such as bodily care of the care recipient through administering medication, patient transport and feeding. Also included in instrumental care is general care efforts such as tending to the care recipients' financial affairs and material assets as these are essential to the success of the care plan overall and are often inextricable from how bodily acts of care are (able to be) performed. All results establish protection of family dynamics as a primary motivator for a subtle approach to addressing infractions. More specifically, corrections aimed at medical professionals indicate a general consideration of family dynamics in adopting a subtle approach. Correction of other familial caregivers lend insight into the unique motivations behind corrections given to lineal and lateral family ties. Lineal corrections (e.g. intergenerational) were more common than lateral corrections (e.g. intragenerational, or a person occupying a similar position in the family such as spouse to spouse or sibling to sibling).

Subtly Correcting Medical Professionals

Data from familial caregivers of the dying indeed show that subtle correcting of medical professionals occurs in the context of end of life. In these cases of subtle correction, a clear care infraction committed by the medical professional was identified by the respondent, yet despite often glaring infractions, familial caregivers opted for a subtle approach to caregiving correction. All corrections were initially motivated by an attempt to improve the care their dying loved one was receiving. A subtle approach specifically (as opposed to a possible overt approach) was chosen after the respondent accounted for family dynamics of some form. The family dynamics considered included (but were not limited to) the express wishes of the dying patient, caregiving boundaries previously established by multiple familial caregivers, or anticipated fallout among family members if a more overt corrective approach were used.

Sandy was caring for her husband who entered in-home hospice after battling prostate cancer. Her husband placed strict limitations on provided by other family members that rendered Sandy the sole familial caregiver, but he did allow hospice professionals to be a part of his care team. While Sandy was the primary caregiver, nurses helped her with particular tasks from time to time. Having retired after a long career in nursing Sandy knew that standard protocol dictates that the nurses should be wearing masks while performing certain care tasks for her husband, such as during wound cleaning. Here, Sandy recalled one such instance where she expected a nurse to be wearing a mask, but they were not. Upon realizing this, rather than asking the nurse to don a mask, Sandy asked *her husband* if he would like a mask and hopes that from overhearing this exchange between Sandy and her husband, the nurse will realize their error and follow suit:

> "LGK: Was there was instance where you had to question an aspect of your husband's care?
>
> Sandy: Yeah. If somebody was doing his dressing or whatever, and they weren't wearing a mask or something. I mean, I know from being a nurse that sometimes you get so wrapped up in the conversation with somebody and stuff you kind of forget the technique. And it's just to ask, "Andy, do you need to put a mask on?" and they're [the nurses] like oh, okay. It was just little things like that.
>
> LGK: Were you ever bothered by that or was just— I'll say it and move on?

Sandy: Yeah, yeah [affirming the latter].”

Recall that in the chapter on caregiver expectations, Sandy’s overall care strategy was that of deferential supporter when caring for her husband. Throughout the interview, Sandy revealed almost no personal agency over the care plan for the duration of her husband’s time in hospice. She attributed this to her husband’s decisive aversion to outsiders being involved in his care. For example, Sandy was forbidden from mentioning her husband’s terminal diagnosis to his children until after his enrollment in hospice care was well underway. Thus, Sandy honored her husband’s wishes by limiting her control over his care and only correcting care improprieties in a subtle way. At the close of the interview Sandy was asked what advice she would give to someone in her same situation and she responded:

> “I would probably tell them that there is a lot of help that [hospice] can offer and *take it!* And even if the person you’re taking care of says no, be a little more proactive in saying ‘No.’ ‘No.’ I would, for me I would just say, ‘okay’, I’ll go ahead and do this or whatever but it’s physically hard.”

Sandy acknowledged how a general lack of personal agency in the care plan colored her entire experience of caring for her dying husband. In the initial quote above, Sandy told of an instance when she took a subtle approach to correcting a misstep in her husband’s care, and the closing remarks of her interview indicate that this subtle correction did little to assuage the feeling that she could, and should, have asserted herself more throughout the care process. The juxtaposition of these excerpts demonstrates how protecting family dynamics (i.e., between Sandy and her husband) served as the primary motivator for the subtly corrective approach Sandy took upon seeing a nurses caregiving infraction.

Bobby’s father entered hospice following a freak accident that sent him to the hospital where medical imaging for his injuries revealed advanced stage cancer. Despite having a brother who lived nearby, Bobby became the sole caregiver for their dying father because the two brothers divided care labor such that Bobby’s brother was the sole caregiver when their mother was dying years prior. Of the care division Bobby recounted: “I was taking care of [Dad] mainly cause [my brother] took care of Mom when she was going through it and he just said ‘Dad's, all yours.’” Here, Bobby began discussing a major theme that prevailed throughout his interview: the isolation he felt throughout caregiving due to his perceived lack of access to familial support. This challenge informed Bobby’s subtle approach to correcting improper care provided by medical professionals, likely because Bobby did not want to alienate the only source of support he had while caregiving. Of his caregiving experience, Bobby confessed:

> Bobby: I was giving everything I had to take care of him. So even though I felt guilty [for not doing more], I don't know what else I could have done deep down inside. I know that I was spent. I didn't have anything left. I honestly was running on fumes all the time and I so much just wanted to say, like ‘Can you like take care of dad for a week’ to my brother, but in the back of my mind I just kept remembering that ‘Dad’s yours, I took care of mom.’
>
> LGK: How do you think your brother would have reacted if you said ‘hey, I really need help?’
>
> Bobby: I think he would’ve helped. I just didn't want to do to him that because he did so well with my mom. I felt like I owed that, you know? I can't go back and help him with her, you know?
>
> LGK: Right, yeah. That makes sense. So were you happy with the hospice care that he received?

> Bobby: I’m very, very, very happy. Yeah. We only complained about one nurse and it wasn't that much.
>
> LGK: What did she do?
>
> Bobby: Oh, I don't know, something very minute, like fluffed the pillow or something. Didn't do it right. It's something very very low. And I talked to her and she was nice and helpful. He made it sound like she wanted to fight him and yell at him, and if she did, she didn't act like that around me.

In this telling conversation, Bobby juxtaposed the support he did not receive from his brother with the support and kindness provided by the hospice nurse (“she was nice and helpful”). Bobby admitted that a care correction occurred, but that the extent of the correction was limited (“we only complained about one nurse and it wasn’t that much”). He felt the support of the hospice nurse so greatly that he approached the correction as a conversation (“I talked to her”) and painted his father as an unreliable narrator who was *really* at fault by making the infraction seem more serious than it was. Bobby ultimately concluded that the infraction must have been as “minute” as an improperly fluffed pillow and thus it warranted only a subtle correction. Additionally, memory of his brother recusing himself from their father’s care was vividly held by Bobby. This became the sole reason Bobby did not seek help from his brother, despite acknowledging that his brother would likely help if only he asked. Bobby honored the previously agreed upon division of care labor, thus this family dynamic effectively cut Bobby off from all other forms of support during the caregiving period except for the support offered by hospice staff. In the face of extreme caregiver burnout felt by Bobby, to correct medical staff in any way other than subtly would risk losing access to the support he so badly needed.

Naomi’s mother entered hospice following colon cancer that metastasized and became terminal. Naomi and her siblings were all heavily involved in their mother’s care, and Naomi was one of the few siblings that lived close enough to offer physical presence and care that other siblings could not due to geographical distance. After being asked if there was ever a time when she had to advocate for a change in her mom’s care, Naomi recounted an incident where a nurse improperly administered medication to her mother. From her years as a nurse, Naomi knew that the drug Atropine is FDA approved for use in eyes, but it has an off-label use of clearing up phlegm in the lungs when administered orally. Naomi’s mother was receiving hospice care in an assisted living (not hospice) facility; thus hospice nurses ordered her mom’s medication and facility nurses administered them:

> “What I did do is, the nursing home nurse made a mistake [giving] Atropine […]. You can give Atropine eyedrops, but you give them in the mouth, to dry up secretions […]. So, this nurse had ordered that […] and said, “we can dry that up that rattle.” […] and of course in our mind when hospice starts the hospice nurse is gonna be here all the time when in fact the facility nurse gives the medication. So, the nurse that night comes in gives the atropine in my mom’s eyes! […] So I sat there and I waited. I waited for a while. And then I thought, I’m not gonna call the hospice nurse. I’m not gonna confront the facility nurse, I’m not gonna confront her because we have tension because our sister has been tense with people and questioning things. […] So we were all in the room and I said ‘I’m gonna call the hospice nurse and make sure that those atropine drops were ordered sublingual or orally.’
>
> So, I stepped out and I called the hospice nurse then she called me back. I stepped out in the hallway and she said, “They were supposed to given sublingual, under the tongue or in the mouth.” She said, “I will call the front desk, and make sure that that is cleared up, I’ll take care of that.” So, she did and I come back into the room, and that [facility] nurse was at her medication cart. After getting the phone call from the hospice nurse she looked at me and she goes, ‘Why didn’t you come to me and ask me? She goes ‘That hospice nurse wrote this order wrong. I gave it how it’s supposed to given. I’ve given many

> medications to hospice patients for years!' She goes 'I gave the right way. She [the hospice nurse] did not write it the right way.'
>
> Well that's not true. If she'd given hospice medications to many hospice patients, she would've known that atropine eyedrops are given orally to dry out the secretions. So she confronted me in the hallway and she was like 'Why did you call that hospice nurse? Why didn't you come to me and talk to me first?' I go 'You didn't order it. I just wanted to go to the hospice nurse and clear the order up.' And so, I'm not going her. I'm not going to question her."

From years of experience as a nurse, Naomi knew without a doubt that the medication ordered for her mother had been inappropriately administered. Rather than using this knowledge to directly correct the actions of the administering nurse, Naomi grappled with whether or not to correct the infraction ("So I sat there and I waited, I waited for a while") before ultimately deciding to approach a *different* nurse. Naomi was then approached by the administering facility nurse who questioned why Naomi did not say something to her directly, thus indicating that the facility nurse is the one Naomi should have complained to. Naomi herself knew that the facility nurse was to blame ("Well that's not true, if she'd given hospice medications to many hospice patients she would've known that atropine eyedrops are given orally to dry out the secretions"). By not asserting her medical knowledge or confronting the administering nurse, and instead self-limiting her corrective approach by correcting the improper medication administration through and off-site nurse, Naomi engaged in subtle care correcting of medical professionals. When asked for the familial context of this incident, Naomi revealed that her sister's interactions with medical staff were a major consideration in how Naomi responded the infraction:

> "You don't want to piss off the people at the nursing home. And actually, my sister did because she had the reputation [with] the other nurses, then the nursing

> home the administrator, and the social worker at the nursing home! The social worker, the administrator, and the nursing team and the aids knew my sister as a person that was difficult to deal with. She raised her voice to the administrator, and like we were like we need to try this over because these people are taking care [of Mom].”

Because of her sister’s previous conduct with the medical staff, Naomi decided to use a subtle approach to correcting the facility nurse. Although this action achieved the opposite of keeping cordial relations with the nursing staff, Naomi’s original intent was to smooth over or at least not exacerbate the tensions originally created by her sister.

Subtly Correcting family

While corrections to medical professionals indicated a general consideration of family dynamics as a motivation for a subtle corrective approach, subtle corrections to family were undertaken specifically to *protect* family dynamics. Further, examining subtle correction of family caregivers by distinct family ties reveals motivations behind protective efforts. Subtle corrections aimed at lineal (or intergenerational) ties were undertaken to keep family ties harmonious while attempting to influence the level of involvement other family members had in caregiving. Subtle corrections to lateral (or members similarly positioned in the family) ties were undertaken to avoid pushing the limits (often emotional) of another familial caregiver, or avoid pushing the limits of the family tie (i.e. exacerbate tensions) a respondent had with another familial caregiver. Lineal corrections were more common than lateral corrections. This difference in prevalence was likely due to overall care strategies of deference to the dying person and fact that many respondents were caregiving for a dying spouse.

Subtle Lineal Corrections

Corrections within the lineal family tie occurred when a respondent corrected the behavior of their intergenerational family member to modify their level of involvement in caregiving to increase the quality of care their dying loved one received. One such instance was found in the lineal tie between Brooke, who was the primary hospice caregiver for her father and her mother, Janice. Brooke provided EOL care to her father and then to her mother Janice mere months later. Below, Brooke described the family dynamics between her and Janice as they cared for her father who was dying of cancer. Janice had a difficult time accepting that her husband was dying and continued to administer care that hospice guidelines do not support (i.e. hospice offers comfort care only, not curative or life-prolonging care). In particular, and despite agreeing with Brooke not to, Janice regularly called an ambulance for Brooke's father, administered diabetes medications, and force fed him. Brooke recounted:

> "And then my mom would call the ambulance when things happened, which we had all agreed we would not do. And she tried to sneak medications to him that he wasn't supposed to have, and she basically didn't really go along with what was happening. So, I was sort of trying to manage her, manage the [hospice] caregivers and hold the line with hospice, like this is what we all agreed. This is what we're doing. It was kind of rough, but it went quickly. I mean, the cancer"

Janice acted in direct opposition to the agreed upon care plan, thus presenting almost endless opportunities for Brooke to correct her mother's improper care of her father. Instead of confronting her mother, Brooke continued the care plan her own way. Eventually, the fissure in care plan resulted in Brooke and Janice keeping different notebooks to track her father's needs:

> "So, we had a notebook where we were keeping track of things like how many times he's going to the bathroom, and when you're giving him pain medicine, all that. Then my mom was keeping one separate—she was still trying to check his sugar and all that stuff and we weren't doing that anymore."

Ultimately, Brooke concluded that the only way to address her mother's caregiving missteps was to move her father to facility care: "I was at my wits' end. I felt like I was working harder trying to manage the caregivers and my mom. […] So, I kept saying [to hospice staff], "can we get him in [a local facility]? Is there any way?" And he was doing almost too well, he didn't have any reason to go to [the local facility], but when I explained—and after she had called the ambulance multiple times— [the facility admitted him]."

Brooke's main concern was Janice's improper caregiving and the amount of attention this took away from Brooke's ability to properly care for her father. Brooke rectified this situation, not by confronting her mother who is the source of the issue, but by moving her father to facility care that effectively cut off Janice's involvement. Thus, Brooke guided the care plan by subtly changing her mother's access to care activities rather than by addressing the misstep overtly. After the move to facility care, Brooke described complicated feelings: "It was frustrating. The worst part was that I had to keep a confident look, like… 'It's great', because my mom was completely against it and I didn't want my dad to feel like we were doing the wrong thing." By not claiming direct agency over her father's care, Brooke was left unsure of who would and would not be impacted by her decisions, ultimately worrying if her father's experience of dying well was put at risk. She found herself feigning confidence in the decision to move to facility care as the best way forward.

Vanessa was the main caregiver for her mother with dementia. Her mother's dementia required around-the-clock care so although Vanessa initially provided care in the home, she eventually opted to place her mother into facility hospice care that the family supplemented with familial care as frequently as possible. Vanessa spent much of her day with her mother and wanted more help from her family so she could take a break occasionally. She recognized that with supplemental health from family, Vanessa could get the rest needed to be most effective at caregiving for her mother. She desired help from her nieces specifically because they were State Tested Nursing Assistants with the professional knowledge to provide quality care to her mother in her absence:

> "LGK: Were there any sort of conversations you had with your family members like, hey I shouldn't have to tell y'all this?
>
> Vanessa: All the time. I understood that they had other obligations but I just felt in my head, people tend to do what they want to do. And you make a way to do what you want to do. So if it was important to you, you'd find a way to do it.
>
> LGK: Was there anybody in particular you were having that conversation with?
>
> Vanessa: Well I would have the conversation with my sister about her daughters. And I didn't go directly to them and say you know, 'you guys need to pitch in more'. I would have the conversation with my sister, say why can't they do this? Sometimes I'd have it with my own girls about, well I need you to do it. I was a little more brisk with my kids than hers. I don't want any excuses, I wouldn't be asking you if I didn't need it so that's the end of it, I just need you to do it.
>
> LGK: So what did your daughters say to that?
>
> Vanessa: Sometimes they were compliant and went along without giving me any negative feedback. And sometimes they said, 'well I have this planned and I just can't do it'.
>
> LGK: And what was the strategy behind going through your sister for your nieces instead of directly to your nieces?

> Vanessa: I figured she had more influence with them than I did. And then when it got to the point where I realized that we were going to have to use a facility, I got all kinds of negative feedback about why are you doing this, why are you putting her in a nursing home. And I said because I am only one person, I can't do it all. I said I want to make sure she's safe, that's my concern, I want to make sure she's safe."

Vanessa felt that the best route to involve her nieces more in caregiving was through someone else (i.e., her sister) who would have more sway in convincing her nieces to help. Vanessa contrasted the approach to engaging her nieces with her approach to engage her own daughters. With regard to her daughters, Vanessa felt more comfortable asserting her wishes for the care plan and received mixed results ("sometimes they were compliant and went along without giving me any negative feedback"). Because Vanessa was in dire need of a break from caregiving for her mother, she employed a softer approach to engage her nieces with hope that this would yield a better result than confronting her nieces directly. Vanessa's subtle approach to correction was undertaken to increase the level of caregiving her nieces provided.

Karen and her sisters shared the responsibility of instrumental caregiving for their mother who was dying of dementia in an assisted living facility. Karen's father, Melvin, also provided caregiving to his wife, mostly in the form of companionship and despite her frequently combative outbursts toward him due to her dementia. Karen recalled: "When they start to get dementia […] they have outbursts, just like yell stuff out. Which hurts the person sitting next to [them], which happened a lot with my father— she would just say stuff". Karen further recounted a particularly hurtful incident in which Melvin called her to come to the assisted living facility immediately. Upon arrival, Melvin described having dinner with his wife in the dining hall when she suddenly proclaimed that she wanted a divorce. Because they were sitting at a table with male resident of the facility, Melvin assumed she asked for the divorce because his wife wanted to be with this other man. Karen attempted to smooth the situation with her father and said: “I'm like, Dad, mother loves you. You guys have been married for 60 plus years. Maybe she's gotten an infection or maybe she just doesn't realize what she had said.” Karen later confirms that this is the case after having a conversation with her mother. This incident illustrated the tenuous relationship between Melvin and his wife. This tenuousness became a major consideration in Karen’s subtle approach to correcting her father’s improper caregiving, described below.

Melvin was in ill health himself (eventually entering hospice after his wife’s death) which compromised his ability to offer instrumental care, with one exception— he would frequently bring his wife candy. This became problematic in hospice because his wife suffered from diabetes. Karen recalled initially asking her father not to give candy to her mother, however he did not listen: “The place that they were living had their own little mini store inside of it, you could go down there and get candy bars and get snacks and get treats. So that's what he did. That was his way of keeping her happy. Just surprising her with something little and sweet like that. So, he didn't stop […]. I don’t think it ever sunk in because he was more worried about taking care of her than listening to us.” When the family realized that Melvin was providing candy to take care of and bond with his wife, they softly corrected his behavior, not by censuring the caregiving act, but by cleaning up its aftermath: “And we [the daughters] would clean out her chair […]. I guess he was just trying to pacify his wife and make her happy. His whole goal was to constantly keep my mother happy." While Karen initially asked her father to stop feeding her mom candy, Karen and the rest of the family's correcting quickly lost steam as they realized her father's loving motivation. The family then opted to subtly correct by monitoring the situation themselves for the remainder of their mother's time in hospice.

By using a subtle approach to correction, Karen protected the family tie between her father and mother and allowed her father increased access to caregiving. Her parents had a tenuous tie due to her mother's dementia outbursts that her father frequently took personally. Thus, in this context of diminished opportunities to express love and care for his wife, Karen's subtle correction allowed Melvin to interact with his wife in a loving way, despite the potential diabetes complications if she were to *actually* consume the candy she stored in her chair. It is this unique combination of protecting family ties and using subtle correction to influence another caregiver's level of care involvement that characterizes lineal corrections.

Subtle Lateral Corrections

The need for lateral corrections was identified after a respondent recognized a care impropriety that would potentially compromise the quality of care provided to their dying loved one. Respondents wanted to address improprieties in order to provide better care for their dying loved one, which served as the initial push to make a correction. Respondents were then motivated to proceed with a *subtle* correction because they desired to protect family dynamics in some way. This motivation to protect family dynamics, a motivation also found among subtle lineal corrections, characterized lateral (or intragenerational) corrections. However, among lateral corrections uniquely, a subtle approach was undertaken to rectify improper care while avoiding pushing the emotional limits of another familial caregiver and/or exacerbating existing tensions. Lateral corrections were exclusively corrections from one caregiving spouse to another caregiving spouse, or from one caregiving sibling to another caregiving sibling.

Rosa, alongside her six siblings, was caregiving for her father after he was diagnosed with a rare form of cancer. This cancer is extremely aggressive and is typically diagnosed at late stage, as was the case for Rosa's father. Despite his commitments to making the most of life and maintaining his physical faculties for as long as possible, only a few months lapsed between Rosa's father's diagnosis and his death. Overall, Rosa described an extraordinarily collaborative and harmonious care approach among the siblings. One exception occurred as the siblings navigated cleaning out their father's house to identify the necessities he needed at his care facility while also prepping the house for sale. This task became urgent for two reasons. First, they needed to collect materials to perform bodily care for their father (e.g. getting clothes to dress him in). Second, tending to the care recipient's material assets are inextricable from the success of more hands-on caregiving tasks as these assets often determine the level of care families are able to pay for and the level of time and energy caregivers have to engage in bodily care.

Initially Rosa described the importance of *all* siblings' participation in this task, particularly because of the emotional toll she expected it would take: "We had to clean out my dad's room and we did this before he passed because one we needed to get him new clothes […] We all wanted to do it together, we didn't want that burden on [one sibling]. It’s a huge task and there’s just so much to it. […] I know no singular one of us could’ve done it. […] That was going to be one of the hardest things, clearing out his space. It’s his private space.”

She further described that the family initially agreed that all siblings would help clean out the house: “So we all get this plan and we’re like alright, we’re all going to go and we’re going to at 5 when people get off work.” However, the number of siblings involved quickly decreased as individual siblings expressed boundaries that a “core” group of siblings did not wish to push. Below, Rosa provided a rich account of how some siblings were ‘allowed’ to recuse themselves from this task. Rosa initially rebuked all her siblings’ attempts to not participate, but her approach with her older brother and sister remained subtle and was not pursued to any consequence because she believed they could not handle it emotionally. This stood in contrast to her approach with a younger brother she felt *could* handle it emotionally:

> “So we all get there and we’re like “alright we need to go, we need to go” and my [younger] brother is like off somewhere. And we’re like “[Younger Brother] we have to go, we have to go” and he’s like “well why don’t we just do this later?”... Like “No. We’ve got to do this […]. That was hard, getting everybody to do that, because we could make up various reasons why not, ‘traffic is terrible’… which was one of the reasons. My [younger] brother was like “oh we’re getting into traffic now.”

When asked if it was ever an option to have her siblings be released of this obligation, Rosa contrasted the emotional capabilities of her older brother and sister with those of her younger brother and sister. She stated these capabilities as the reason for why she only subtly corrects her older siblings, while she pushed her younger brother to participate because, despite his protests, *he* could handle it:

> “Rosa: So we kind of said that but none of us meant that. Like it was important for all of us to be there because we knew… Well that isn’t true. My [older] brother was not there for that and he almost didn’t come see my dad in hospice because it was just too much. He’s my oldest brother and that was too much. We did excuse him from these kinds of things because he just couldn’t, it was hard. It was beyond what he could handle emotionally. So we let him process the way he needed to. But with my sister and [younger] brother we’re like “c’mon we got to do this… we got to do this as a group”.
>
> LGK: Was it because you thought that [your younger brother] could handle it or?
>
> Rosa: Yeah. We knew that between the three of us, we could handle it because we’re the closest in age. And we kind of had to at that point. We took up that mantle. I think… You know, that is true, we took those roles and those roles did not change, we as a unit took those roles.
>
> LGK: The three of you? [meaning her younger brother and sister, and her]
> Rosa: Yeah. The three of us out of the rest of us. Because my other sister couldn't handle it. She’s got a lot of emotional problems and she just couldn't handle that either. So knowing they couldn’t handle the emotions of that, we let them deal with it. And they were okay with that too. We’re texting the whole time saying do you want this, do you want that which is the most millennial way we could possibly do that. But it helped everybody because they’re still kind of involved but we were taking on the brunt of that emotional work. And it was okay because there’s three of us.”

By contrasting her corrective approach with her various siblings, Rosa revealed the motivation behind a subtle correction. Subtle corrections (i.e., intentionally limited and to no consequence) were used because they avoided pushing the emotional limits of a lateral caregiver. This subtle correction within a lateral family tie occurred in cases of sibling and spousal corrections alike. For example, below Kim described using a similarly subtle approach to address caregiving impropriety of her husband.

Kim became a main caregiver for her father-in-law after he was diagnosed with dementia that caused him to deteriorate quickly. Around the time of his diagnosis, Kim’s mother- and father-in-law moved into a house next door so that the families could be close together and have a more convenient way for Kim and her husband to be involved in caregiving. Despite this intention, Kim's husband did not participate in caregiving and did not even visit with his father during his time in home hospice. Kim's subtle approach to caregiving correction of her husband culminated in the final weeks of her father-in-law's life when he began having frequent falls. She recognized that in order to provide proper care for her dying father-in-law, her husband needed to be available should he fall, otherwise he would be left lying on the floor since Kim and her mother-in-law could not lift him:

> "He had fallen a few times in the bathroom […]. Sometimes in the middle of the day [my mother-in-law would] call me and she's like, 'can you come and help me?' and he was too big and the bathroom was too small for us to move him so I'd have to like call [my brother-in-law who] helped get him off the floor a few times. And [my father-in-law is] buck naked and he had no shame anymore because he didn't know what was going on. I mean we had service men on the street come in and lift him up. I was like 'no more bathing him when [my husband is] not at home. [My husband] doesn't have to be involved in [bathing] but somebody's got to be there.' So yeah so [my husband], just to finish that, I mean my husband never, like he wouldn't go over there to visit."

In this selection Kim first recognized a care change that needed to happen—her husband must be present for her father-in-law's bathing because this was the time he was most at risk of falling. However, Kim did not address this care change directly with her husband, instead opting to tell her mother-in-law of the change that will involve Kim's husband in the logistics of transporting her father-in-law before and after bathing. In the same breath of subtle correction by signing her husband up for care involvement that he has not approved of, Kim stated that her husband would never go over to see his father. Providing context for her husband's lack of involvement in caregiving Kim said, "My husband was really disconnected from everything." Later positing that, "My husband […]

I think really struggled with the early deterioration of his dad." Her supporting evidence for this last statement came from various experiences the couple had with death and dying, namely the death of their beloved family dog:

> "Going back to my husband and his dealing with [death], we have a dog [currently, but] the other dog we probably had to euthanize about seven years ago. She was a dog that my husband had when I met him but she kind of became my dog because when I met him and I moved in here I was working on my dissertation and I was taking care of the kids and working from home and so I watched her get sick. And her limbs just were all... I mean she would just splay out and she couldn't even stand up. So, I was trying to convince him for like six months that this dog is at the end and she was suffering. It took a very long time for me to convince him to euthanize her. And when his dad was getting sicker and sicker and I would talk to my mom about, well how do you talk to people about the reality of like [what is happening]?"

Through Kim's own experiences with death and the influence of her parents who are physicians that talk frankly about death, she became comfortable with the idea of death early in life. Kim further recognized that her husband did not have the same relationship with end-of-life and that death was a difficult subject for him to grapple with. She directly related his inability to accept the deterioration of the family dog with the deterioration of his father's health and posited this as the major explanation for why her husband did not involve himself his father's care or companionship while in hospice. Kim often sought her mother's advice for how to broach the subject with her husband but during our interview she never spoke of *actually* addressing the issue with her husband. Upon her father-in-law's death, Kim described, "my husband had disconnected from the whole thing because his dad wasn't there. He said, when the funeral finally came, and it was sad, but he hadn't seen his dad in a long time as his dad." Of her own processing she said, "For me, I really didn't mourn [his] loss because I really didn't ever feel like I knew him. So I felt a lot of relief that the whole thing was just over. We'd never talk about it every day anymore and just the stress around it... it's really just been managing other people's feelings around it."

Together, the components of Kim's story illustrated how much her husband struggled with recognizing the reality of his father's dying. This struggle continued throughout the entire hospice period and was a deciding factor in how Kim addressed the caregiving inadequacies created by her husband's lack of care participation. Only the in the extreme circumstance of unmitigated falls during bathing prompted corrective action from Kim, however that action was subtle. She rebuked her husband's lack of care in conversation with her mother-in-law and volunteered her husband's services without his consent. Further, knowing the difficulty her husband would face at having to intimately witness his father's physical deterioration, Kim explicitly stated that her husband will not help with bathing itself, only with lifting after bathing has occurred. In line with this, Kim named managing other's emotions during coordination of care, such as the emotions of her husband, as the most taxing element of her caregiving experience: "I felt a lot of relief that the whole thing was just over. We'd never talk about it every day anymore and just the stress around it... it's really just been managing other people's feelings around it."

Finally, recall Naomi who used subtle guiding of medical professionals in the section above. With her family, Naomi used a similarly subtle approach to speaking out against her sister who frequently disagreed with the care plan desired by Naomi and her brothers. Naomi and her brothers believed that the best care for their mom would be offered through a facility, but Naomi's sister struggled with the idea of moving their mother to facility hospice because it would make their mother's dying undeniable. Below, Naomi described this dynamic as it played out in decision-making around enrolling their mother in formal hospice care:

> "LGK: Is there a situation that you imagine that you would say, "I can't worry about my sister's feelings at this point". Something that would happen with your mom or with other family where you'd say, "okay I need to speak up"?
>
> Naomi: I tried to speak up, when my brothers would go check on my mom during the home health visits. And initially when we left the appointment when my mom stopped the treatment at the first part of October, we were like "okay, let's get this going." And she was like, "Okay"— my sister was okay. And then I think she thought about it and she said, "I want to try home health." So, I tried to speak up then. I think when my mom was declining and my brothers would be out there my mom would say, "I'm tired of these people coming out." I texted my sister and I said, "Are we on board? Can we go ahead and try hospice now? Can we try this?" because I felt like we were at a point where we need to get hospice going on home health. And I did speak up. It was through a text though. I said, "I think we need to be ready and get going on this." And she didn't answer until the next morning. "I'm not ready to do this." So that I guess that I tried to?""

Naomi and her brothers wanted to move their mother to formal hospice care in a facility, a plan that differed from the desires of their sister. When asked how she might "speak up" in instances of conflictual care plans, Naomi provided the example of asking her sister questions to assert the wishes of she and her brothers. Naomi's confrontation with her sister over the conflictual plans happened over text message exclusively and she used soft language to frame what Naomi viewed as speaking up ("*can* we try this?", emphasis added). Naomi's sister responded with "I'm not ready to do this", clearly articulating a personal emotional boundary and truncating Naomi's corrective efforts. Naomi herself indicated a lack of fervor in her approach, asking "So I guess that I tried to?" Despite Naomi's and her brothers' agreement on the desired care plan, both Naomi's initial approach to the subject and subsequent action following her sister's boundary setting are limited to subtleties to not push their sister who had an extensive history of emotional outbursts in relation to the caregiving efforts of both family and medical staff.

Discussion

Care negotiations between patients and doctors rife with care corrections are well understood, yet similar understanding of the role of family caregivers in negotiating care on behalf of a dying patient is lacking. Subtle corrections (i.e. attempts to alter a caregiving act performed by another caregiver where the corrective approach was *intentionally* limited and/or the limited approach did not lead to a change in the care plan) are a prevalent form of care correcting behavior as evidenced in various contexts including parents seeking antibiotic treatment for their children, parents attempting to influence care provided to their terminally ill children, and spouses undertaking healthcare work to promote spousal medical care. However, previously unknown is whether familial caregivers of the dying engage in subtle care correcting and, if they do, what motivates their subtle approach to care correcting. The current research establishes that familial caregivers of the dying *do* engage in subtle care correcting of both medical professionals and other familial caregivers, and that consideration of family dynamics in some capacity motivates their subtle approach to correction.

In-depth interview data from 25 familial caregivers of a person in hospice reveal nuances in who familial caregivers subtly correct and the motivations behind those corrections. Familial caregivers of hospice recipients corrected the caregiving efforts of both medical professionals and other familial caregivers. In all cases, the need for a care correction was motivated by the respondent’s desire to improve the quality of care provided to their dying loved-one. Beyond that, a subtle approach to correction was motivated by the caregiver considering family dynamics in some way. In these cases, a clear care infraction performed by a medical professional was noticed by the caregiver. Despite these obvious infractions, respondents responded with subtle correction, rather than a possible over correction. A general consideration of family dynamics was found to motivate the subtle nature of corrections launched at medical professionals. Said differently, familial caregivers who subtly corrected medical professionals were motivated by thinking about or acknowledging the effect of correction on a family member or family relationship dynamic. Specific motivations included honoring the previously stated wishes of the hospice recipient, respecting the caregiving boundaries previously established among caregivers in a given family, or the anticipated negative consequences on family functioning if a more overt corrective approach were used.

Among corrections aimed at medical professionals, worth noting is the presence of familial caregivers with previous medical knowledge, who presumably possess sufficient levels of CHC that would be indicative of their ability to effectively care correct, as has been found in previous research (see Gengler 2015). The occupations of these caregivers (as nurses, medical assistants, emergency medical technicians, etc.) should have afforded them a level of cultural health capital to potentially engage in more overt forms of correction. However, the results here illustrate the power of family dynamics to inform a *subtle* approach to correction. CHC predicts that if an individual possesses adequate CHC they will have the ability to care correct when a care infraction occurs. Conversely, if an individual does not possess adequate CHC they will lack that same ability and thus not engage in effective care correction. Thus the ability to care correct, or the degree of effectivity of care correction, is dependent upon individual CHC. However, results of the current study indicate that family dynamics, and not CHC, serves to limit the corrective capacity of familial caregivers in the context of EOL. A lack of cultural health capital or flexible resources do not explain why subtle (i.e. constrained, or not overt) corrections occurred, but a respondent's accounting for family dynamics did. Concretely, findings in the current study render CHC and FRT insufficient explanations of the corrective efforts of familial caregivers in the context of hospice.

The privileging of family dynamics as a motivation for subtle correction is mirrored in results of corrective action aimed at other familial caregivers. The current study establishes that care corrections *between* family members does occur in the context of EOL care. Further, corrections between familial caregivers go beyond a respondent's general consideration of family dynamics (as seen in corrections of medical professionals) to illustrate the importance respondents placed on *protecting* family members or the family itself in addition to the initial correction motivation of protecting the quality of care provided to the dying person. Subtle correction was given to both lineal and lateral family members, leaving no family member immune from correction in the presence of impropriety.

Lineal corrections (e.g. intergenerational) were more common than lateral corrections, likely due to the combined factors that many respondents were caregiving for a dying spouse and the pervasiveness of deference to the dying person. Lineal subtle corrections represented attempts to influence the level of involvement the corrected family member had in caregiving. This finding is reminiscent of evidence that spouses use indirect techniques, for example destigmatization, to increase their spouse's involvement in formal medical care for mental health concerns (Reczek et al 2020). Lateral corrections were decidedly subtle to avoid pushing the (emotional) limits of another familial caregiver or to avoid exacerbating existing tensions between family members. Thus, the present study establishes the different care correction motivations that occur according to where the correction receiver is located in the family. Specifically, subtle correction to lineal ties were motivated by a desire to influence (most frequently, increase) the level of involvement of other familial caregivers. Whereas subtle corrections to lateral ties were motivated by a desire to not create potential or exacerbate existing family tensions.

The present findings of lineal and lateral corrections advance previous work on within the doctor-patient dyad and corrections between family members in important ways. By going beyond how these interactions occur between the care corrector and the correction receiver, the present study explores how these interactions are manifest in *actual* care. The present study establishes the dynamics between how an individual caregiver’s care logic becomes the tangible care they provide. Findings of the constraining effect of family on this process also highlight the complex network one must navigate when administering a subtle care correction. This research questions the applicability of a strictly dyadic (i.e. patient-doctor or spouse-spouse of previous research) understanding of care negotiations in the context of caregiving for the dying.

Previous inquiry had yet to explore (1) whether subtle care correction occurs in the context of EOL care and (2) if care corrections do occur, what motivates them. Existent knowledge on care correction centralizes the explanatory power of CHC and RTC, but the applicability of these theories to explain experience of EOL caregiving was previously unknown. The current study sought to address this gap and established that subtle care correction does indeed occur in the context of EOL care and that subtle care corrections can be launched at all members of a caregiving team including medical professionals and other familial caregivers. Further, although distinct motivations for subtle care correcting were found, and all motivations began with a desire to improve the care provided to the hospice recipient and all corrections were subtle in nature because of respondents taking into account family dynamics in some form. Taken together these findings indicate that much of the EOL caregiving experience is characterized by subtle (defined as limited) forms of correction. One way to interpret the pervasiveness of subtle correction is as an unveiling of the largely constrained EOL caregiving experience, at least where subtle care corrections are concerned.

Familial caregivers of the dying indicate that the subtle (or limited) nature of correcting care impropriety that might negatively impact a dying loved-one is subtle because the correcting party is constrained by family dynamics. This constraint may be the result being mindful of family dynamics in general (as seen among correction of medical professionals). It may be the exchange one makes in order to garner caregiving support from other family members (as seen among lineal care corrections). Or it may be the cost one pays to protect family members or family dynamics (as seen among lateral familial corrections). Thus by using subtleties in the face of care improprieties that are consequential to the dying persons experience, and because of the family, the individual compromises their agentic power. To protect the family is to compromise the self.

While outside the scope of the current study, it is possible that the compromising of the self for the family occurs in the context of hospice care because matters of EOL are rife with normlessness. Familial caregivers of the dying become primary caregivers for a person they love who has never died before and thus each caregiver enters unchartered waters. Perhaps the subtle nature of correcting care impropriety occurs because more overt efforts risks a caregiver's access to the family, a pillar of social life that may offer some sort of organization (or commiseration) for the caregiver during a time of acute normlessness. Or perhaps constraining individual agency in care correction is a welcome exchange as the exercise of personal agency is not the goal of EOL care. Regardless of whether individual constraint is willingly offered or reluctantly adopted, the present findings leave one to wonder: when, if ever, are familial caregivers of the dying able to claim agency over their experience

Chapter 4. Protecting End-of-Life Values: How 'Mortality Beliefs' Inspire Caregivers of the Dying to Exert Agency over the Care Context

Introduction

The diverse efforts of end-of-life (EOL) research enumerate the various social actors, institutions, and structures that comprise the dying process. These efforts serve to better understand how dying is experienced and most prominently pursue the implications of such research for how dying is experienced by the dying person specifically. Emphasis on the dying person's situation makes sense, particularly when considering that in modernity health and well-being is a fundamental human right (Brennan 2007). Within this framework an actively dying person represents a likely site where the negotiation of health and well-being rights occurs, and when rights are at stake the agentic action of stakeholders is inspired (Buchbinder 2018). Health agency refers to the ability of an actor to make a choice among options (Elder, 1994; Hays 1994). In practice, enacting health agency (or agency over health) typically, but not always, involves some sort of advocacy for the self or others. Much of our understanding of EOL health agency is born of studies on macro-level health advocacy such as through lobbying for patients' right to die (Buchbinder 2018; Best 2012), down to micro-level advocacy like a dying person codifying EOL wishes in legal advanced care directives (Seelman et al 2019). These EOL health efforts serve primarily to benefit the options of agentic choice available to dying persons.

By asserting agency in various ways larger social values are revealed. Values in this sense refer to social ideals that reflect "(a) concepts or beliefs, (b) about desirable end states or behaviors, (c) that transcend specific situations, (d) guide selection or evaluation of behavior and events, and (e) are ordered by relative importance." (Schwartz & Bilsky 1987, in Hitlin and Piliavin 2004). Much like EOL agency, EOL values are once again existent at all strata of social life. EOL values are reflected in macro-level structuring of the hospice economy (Livne 2014), meso-level medical practice of medical examiners (Timmermans 2006), and micro-level prioritization of patient individualism in how doctors approach decision-making conversations with EOL patients (Buscariolli and Mikko 2021). Again similar to our understanding of EOL agency, EOL values are reflective of justifications behind the protection of dying persons rights.

However, making the implicit assumption that agentic action and values should be oriented toward the situation of dying persons alone obscures the agentic needs and actions of familial caregivers of the dying who are key actors in the dying process. There is reason to suspect that agency of familial caregivers of the dying is compromised as physicians describe familial caregivers' potential agency as "weak and vulnerable" (Buscarolli and Mikko 2021). Yet, how familial caregivers of the dying assert their agentic power over the care context remains unknown. Understanding the agency and values of familial caregivers of the dying is of paramount importance not only because it holds implications for *their own* access to rights and well-being, but it holds direct implications for their ability to effectively care for a dying loved one.

In response to these gaps in our understanding of EOL agency and values, the present study seeks to answer two central questions: (1) how do caregivers of the dying explain their choice to exercise agency in the care context? And (2) what social values are reflected in exercises of agency performed by caregivers of the dying? Answering these questions required analysis of in-depth interviews with 25 familial caregivers of the dying. In familial caregivers' detailing of navigating care they reveal three distinct values used explain their agentic choices and actions. Reflected in their stories are values of identity, objectivity, and justice.

Results establish that caregivers of the dying explain the choice to exert agentic power over the care context because of a desire to uphold *mortality beliefs*, a concept pioneered in the present study. Mortality beliefs encompass the values so strongly held by caregivers of the dying that agentic action is inspired. Specifically, mortality beliefs describe investments in preserving identity, seeking objectivity, and ensuring justice in the context of EOL care. These findings first expand our current knowledge of EOL by providing an account of how agency over care manifests among familial caregivers of the dying. Second, the present study names the specific values leveraged by caregivers and offers new understanding of how larger cultural EOL values do and do not map onto the experiences of individual caregivers. Finally, the present study makes the connection between caregiver agency and values explicit. In doing so the present study amends the oversight of previous research (that itself has reflected narrow EOL values) which has unintentionally positioned caregivers as background actors in dying by excluding investigation of the agentic power familial caregivers exert in the dying process.

Background

Agency in Health and at End-of-Life

Sociological efforts position agency as existing in opposition to or embedded with structure and extensive research efforts center on defining, explaining, or understanding agency. Giving a comprehensive definition, Hays (1994) conceptualizes agency as existing on a continuum. At one end of the continuum, actors possess complete control over their social world because they are the architects of social structure: creating, altering, or destroying social structures as they see fit. At the other end of the continuum, actors are simply the “carriers” or “instruments” of a social structure that exists irrespective of the actor’s individual will. Conceptualizations aside, in the actual social world, agency is experienced somewhere in the middle of these poles and people exercise agency by making a choice among a finite number of choices (Elder 1994). In this context actors typically make choices that reproduce, rather than disrupt, a given social structure (Hays 1994). Modern understandings of agency in the social sciences further elucidate that agency can be enacted toward or over the self, other actors, larger society, and even extend to abstractions like equity or truth (Meyer and Jepperson 2000).

Agency becomes of paramount importance in issues of health when considering modern emphasis on health as a fundamental human right (Brennan 2007). Positioning health in this way forces social reckoning with issues of equity and social justice and their dialectical relationships with agency, and actual social life reflects this as research on healthcare advocacy shows. In many ways, healthcare advocacy is the modern language and/or vehicle for health agency in both the macro and micro levels of social life. Advocacy in this context refers to “activities related to ensuring access to care, navigating the system, mobilizing resources, addressing health inequities, influencing health policy and creating system change” (Hubinette et al. 2017). At the macro-level, increased advocacy (in the form of organizational lobbying for equitable distribution of health resources, recognition of stigmatized or contested disease, etc.) has been so consequential that it has come to alter the social contract for science (Best 2012). Unprecedented advocacy of this kind challenges scientific autonomy and alters the production and distribution of (medical) knowledge, in large part due to the increase in lay expertise in matters of health (Best 2012).

At the micro-level, patient agency in health, or the “freedom from unnecessary suffering,” requires direct attention be paid to those at EOL (Brennan 2007). Individual action indeed supports this assertion, as research on advanced life planning illustrates distinct motivations for the desire to plan. Namely, adults actively seek and complete advanced life planning for three primary reasons: (1) reducing conflict and confusion for loved ones, (2) attempting to learn from the (in)actions of others, and chiefly (3) obtaining a sense of agency over their life and health (Seelman et. al. 2019). While some individuals can exercise preemptive agency over their health at EOL, that is not the case for everyone. Findings on assisted suicide, hospice, and palliative medicine illustrate how a delicate balance between the wishes of the patient and the family is desired for EOL medical decision making (Hawkins 2017).

Despite encouraging findings of this delicate balancing, and the preemptive agency found in EOL planning, there is reason to be skeptical of existence of agentic power at EOL. For example, medical doctors' themselves characterize patient agency at EOL as "weak and vulnerable", particularly when compared to the agentic capacity of medical professionals to proxy a patient's agentic power (Buscariolli and Mikko 2021). Within this inconclusively of current understanding, micro and macro manifestations of health agency highlight how inextricable health and agency are from one another, yet we lack an account of how agency manifests among prominent actors in dying— familial caregivers.

Values of End-of-Life

To understand the agentic capacity of caregivers is to only scratch the surface of useful knowledge of how death/dying is navigated. Agentic action must be inspired by or in pursuit of something and looking to what is valued at EOL can elucidate the driving forces of agency. Values in this context refer to ideals of death/dying itself and serve as the link between the "antecedent social positions and the individual choices" of actors that then make up social structure (Hitlin and Piliavin 2004). The undercurrent of values of EOL are (said somewhat optimistically) oriented toward some degree of taking the best possible care of the dying patient. After all, life is seen as sacred and worthy of being protected (Ekland-Olson 2012). However, as medical technology continues to increase the ability to keep humans alive longer, new issues of inequality and moral values arise in the balancing of protecting life with ensuring quality of life (Ekland-Olson 2012). Recognizing these potentially competing desires for EOL, interrogating a multitude of intersecting and overlapping values in EOL is ever-relevant if we are to comprehensively understand how individuals come to agentically navigate EOL processes.

Economic Values

A macro-level examination of dying illustrates the salience of economic valuation and how it manifests in the death industry. Investigating modern economic values in dying reveals an intimate intertwining of moral and financial values. At the level of financial markets, Quinn’s (2008) examination of death benefits (the buying and selling of life insurance policies in particular) reveals a kind of dance that unfolds between proximity to the financial industry of dying and moral valuation of the economy of dying/death. To examine this dance, Quinn isolates the secondary market for life insurance policies where institutional entities purchase policies from those participating in the primary market (i.e. dying persons themselves). Quinn finds that those least proximate to the secondary market (e.g. news media reporting on the market’s dealings) abhor the existence of the market, characterizing it as one that preys on the vulnerabilities of the ill and their families. Among professionals working on the periphery of secondary market sales, moral value is attached to the secondary market and those morals justify the market’s existence. This justification states that the market provides a social good of allowing families to access money to provide care they would have otherwise been unable to afford. These findings stand in contrast to the findings among those closest to the market (e.g. a purchaser in the secondary market) who view the buying and selling of death benefits as typical market activity thus attaching no moral valuation to their dealings. Together Quinn’s findings confirm the intertwining of moral and financial values at end of life and highlight the variation and complexity within this intertwining (Quinn 2008).

In hospice care, a similar intertwining of moral and financial values occurs and is notably displayed in Livne's work on the "moralization of scarcity" (2014). In this context, scarcity can refer to the withholding of specific treatments (such as choosing a less effective medicine because it is cheaper than a more effective one) or the withholding of treatment altogether (for example by not prescribing antibiotics or ordering transfusions). Scarcity helps ensure the continued existence of the hospice industry because it allows individual hospices to control financial flows via investing less in expensive treatments. This financial motivation is morally justified by the belief that withholding treatment allows disease to progress naturally and in a way that enables patients and their families to accept an inevitable death. While economic values feature prominently in how the dying financial market and hospice itself is structured, it remains unknown whether economic values factor into how familial caregivers of the dying navigate their caregiving.

Scientific Values

Scientific values as they relate to death and dying are present in all strata of social life from how the medical field is oriented to how individuals' deaths are understood and navigated. In all strata, the notion of objectivity in death and dying is enthusiastically valued (note that whether objectivity is achieved is questionable). Objectivity in this context refers to "the collective production of evidence" (Cambrosio et al. 2002). Beginning with the structure of medicine itself, a relatively recent shift in the ethos of medical practice has marked movement away from eminence-based medicine, where unique standards of care are established by individual doctors, and toward evidence-based medicine (EBM), where a single field level standard of care is established through an ever-growing body of scientific research and findings (Timmermans and Oh, 2010).

In accordance with EBM and the objective standards of care it seeks, clinical judgements, such as determining a cause of death, are thought to be easily defined through biomedical processes. However, in practice, cultural clues interpreted by medical examiners inform cause of death determinations as much, if not more, than biological clues in many instances (Timmermans 2006). In turn, interpretations by medical examiners are influenced by larger cultural values when picking between the possible official options for cause of death. Cause of death options include “acceptable” or “good” classifications (such as natural, accidental, and in some cases undetermined) while other options (such as suicide and homicide) carry a negative connotation. For example, in the context of infant death, there is no “good” or “acceptable” manner of death and cause of death determinations are made accordingly. In contrast, among adult decedents medical examiners (consciously or unconsciously) use elements of their assumed identity (such as race or class) to interpret the context of their dying and assign cause of death accordingly. Thus, despite the medical authority found in the medical examiner profession, and although objectivity of practice is desired, larger culture values come to bear on how the circumstances of an individual's dying are interpreted and cause of death is assigned.

The value of objectivity of medical practice in matters of death, and of medicine itself, is also reflected in the micro-level medical practice of physicians treating patients at EOL. Palliative care processes illustrate the desire for objectivity in care and this is most notably seen in how care decisions are made. Specifically, care conversations between doctors and patients/patient's family “[transform the] volatile and possibly momentary feelings” of care receivers and their family’s wishes for care into “a fixed set of personalized traits” through medical and legal documentation related to care (Livne 2019). In the filling out of forms and other acts of care decision making, doctors understand the “morally unsettling” nature of the task at hand (Livne 2019). When the course of a palliative care plan is uncertain, doctors actively seek confirmation that their recommended course of action is accepted by the family and patient (Livne 2019). This can be viewed as doctors attempts to grasp at a version of objectivity because to seek patient and family confirmation is to actively incorporate diverse perspective so that the doctor's perspective alone does not influence care.

Individualistic Values

Protecting and promoting patient autonomy at EOL is at the core of western bioethical values (Volker 2005). The centrality of maintaining patient autonomy can be seen not only in the care decision making processes of medical professionals and those nearing EOL, but also in the effects of caregiving on caregiver health and well-being. Regarding decision making processes, older persons drafting advanced care directives identify autonomy, identity, and efficacy as key considerations for mapping desires for their EOL experience (Wilkinson 2017). Similarly, among community dwelling older adults, individualism (over collectivism), independence (over interdependence) and self-reliance (over interconnectedness) were identified as essential values of an EOL experience (Bullock 2011). Mirroring this enthusiasm for patient autonomy, physicians of the terminally ill “express distinctly positive attitudes towards patient autonomy”

(Buscariolli and Kari Mikko 2021). Enacting this enthusiasm, palliative care doctors helping patient and their families navigate EOL care make direct attempts to engage the personhood of care recipients by supporting patient driven decision making to the extent possible (Livne 2019).

Commitment to the dying person’s autonomy at end of life is also evident in the efforts and effects of caregiving for those at EOL. Take for example the efforts of adult caregivers of persons experiencing bodily decay (or failed bodily functioning). As suggested by research on parents requiring intensive care associated with incontinence, caregiving is characterized by an intense negotiation of power between care giver and receiver (Isaksen, 2002). This negotiation of power results from each party's awareness of the implications of intimate care on perceived independence. Caregivers in this context must navigate the competition between performing necessary intimate care tasks with mitigating the loss of independence felt by the care receiver (Isaksen, 2002).

Given such a fraught caregiving context, it is easy to see how caregiving for a dying loved one can compromise the health and well-being of caregivers. In executing their duties, caregivers of the dying serve as not only the primary caring figure, but also the primary protective figure—immense responsibilities that may contribute to caregiver overburden (Soto-Rubio et al 2017). In turn, caregiving overburden is associated with higher levels of anxiety and depression that are seen among familial caregivers of the dying (Northhouse et al 2012). Further, among caregivers, women experience more mental and physical strain than male caregivers due in part to larger cultural notions that women are more responsible for the EOL caregiving of family members than men

(Morgan et al 2016; Pinquart and Sorensen 2006). Additionally, regardless of caregiver gender, the emotional distress of a caregiver has a reciprocal relationship with the cognitive state of care receiver (Soto-Rubio et al 2017), thus as patient well-being decline occurs (as is inevitable in actively dying persons), a corresponding decline in caregiver well-being occurs. Findings such as this highlight the necessity of also centering death and dying research on the experience of familial caregivers, even if care receiver individualism is seemingly valued above all else (Soto-Rubio et al 2017).

Methods

Below I detail methods relevant to the current chapter. For a full description of the study methods, refer to chapter one.

Data Analysis

The data below represent the instances where a respondent exercised agency within the care context. Exercises of agency were found when a respondent made a decision and effort to exert control over some aspect of the caregiving context. As is found in previous research, these agentic actions were diverse in nature and included agency enacted on behalf of the self, a dying family member, hospice as an institution, or even agency enacted in service of equity or truth (Jepperson 2000). Further, agency frequently (but not always) came in the form of self or patient advocacy specifically. More rarely, agency took the form of more general respondent driven (and decisive) care planning.

To elucidate the motivations behind agentic action in the context of care for the dying all data present an extensive caregiving narrative. Through these narratives all respondents point to some misgiving in care and these misgivings were as diverse as the caregiving experiences of respondents themselves. The nature of these misgivings exhibited no notable patterning: some resulted from the actions of a medical professional while others resulted from the actions of other familial caregivers; some misgivings were the result of hospice facility failings while others were the result of institutional failings. Although their shape differed, all misgivings served as an initial alert to an element of care that (potentially or actually) compromised caregiver or receiver well-being. Prompted by this, respondents exercised agency to address the misgiving. It is the values reflected in the decision to exact agency that is the focus of the current study. Uncovering these processes of why respondents translated alerts of a misgiving in the care context into agentic action allows two central research questions to be answered: (1) How do caregivers of the dying explain their choice to exercise agency in the care context? (2) What social values are reflected in the exercises of agency performed by caregivers of the dying?

To this end the following interview questions were analyzed: Did you ever have to advocate for a change in the plan? How did you do this? Did you have any allies in this? How did you feel during this time?; Did you ever disagree with a part of the care plan? Why? How do you deal with this?; Who has more bearing on what your care plan looks like, medical professionals, you, other family members, or your family member? Why is that so? Are you happy with this? Was this always the case?; How has your experience matched up with what you expected of Hospice care? Clear patterns emerged in the reasons why respondents engaged in agency over their caregiving experience. As a result, this study pioneers the concept of *mortality beliefs* to understand the EOL values that are connected to agentic action in caregiving for the dying. Specific mortality beliefs found in the context of care for the dying include (1) identity preservation, (2) objectivity, and (3) justice.

Results

While previous research would predict that the experience of caregiving for a dying loved one is a largely passive project, the results below all represent instances of caregivers exerting agency in the care context. The results that follow illustrate the values caregivers used to explain their agentic action. In explaining the circumstances surrounding their decision to enact agency over the care context, respondents reveal the EOL values, or *mortality beliefs*, associated with a desirable EOL or EOL caregiving experience. These mortality beliefs outline that in EOL caregiving identity should be preserved, objectivity should be sought, and justice should be exacted.

Identity Preservation

Exerting agency when giving EOL care resulted when a care related occurrence held implications for either the identity of the caregiver or the care receiver. Specifically, advocacy as a means of agency occurred when a respondent felt identity was being actually or potentially compromised by an act of improper caregiving. Advocacy in this context was used as an attempt to preserve or restore the identity of the caregiver or receiver. The audiences of these exercises of agency were diverse and included state agencies, other familial caregivers, and medical professionals, among others.

During her time in the military, Sam worked in various health care capacities and had basic medic and lifesaving skills. These skills were later augmented by her experience caring for her father who was placed on life support following a major health event. Because of these trainings and first-hand experiences, Sam became invaluable to her mother-in-law’s EOL care. Sam’s mother-in-law suffered from diabetes that made her susceptible to necrotizing fasciitis which eventually became the cause for her hospice enrollment. During the transition from nursing home to hospice care, Sam frequently observed medical staff’s improper wound care. The nursing facility eventually decided that they were not willing to provide the level of care Sam’s mother-in-law required and terminated their services:

> “This is ridiculous. It was basically all over Tegaderm, you know like they would use to cover your IV. But they make huge ones for wound care. Well, they're really pricey and the woman didn't want to pay for it, but the way her wound was set up, it wrapped all the way around her behind. When she would go to the bathroom, it could potentially get on her wound, so the doctor wanted it covered with something that would be waterproof. There were times that she could not get up to the bathroom quick enough so it needed to be protected, it needed to be waterproofed, and they didn't want to do that. So then, they literally discharged her the very next day. They were like, ‘We're discharging her. You're going to have to find somewhere else to send her.’”

Toward the end of the caregiving period with the nursing home, Sam made her care wishes known to medical staff by stating that she would contact regulatory agencies if necessary: “And I gave them a warning, ‘I'm going to do this [call state regulatory agencies],’ and then when I went back up there that night, after all management had left and only the night shift nurses were there, her dressing change had still not been done properly. I was like, ‘Okay, I gave you the opportunity. You said you have the stuff here, you said you would follow the instructions, but you did not.’”

At this point in the care plan Sam began transitioning her mother to a hospice facility that would administer proper care. Despite the severed care relationship with the nursing home, Sam continued to advocate for her mother-in-law's care by involving state agencies: "I called the State Department of Health and the Board of Nursing and there was a state surveyor in there the next day. Because when I say I'm going to do something, I do it." Sam engages in an ultimate form of advocacy by contacting state regulatory agencies, even though her mother-in-law is no longer receiving care from the nursing facility. In justifying this act of agency, Sam invokes her personal identity as a driving force ("when I say I'm going to do something, I do it"). For Sam, to not call regulatory agencies after saying she would would betray her sense of personal identity. Thus, to protect her identity Sam engaged in self advocacy. In doing so Sam is motivated by a need to protect her mother-in-law's care quality, while also revealing a deeply held mortality belief in EOL care—when identity is at stake, advocacy is justified.

In caregiving for her mother, Cassie encountered a situation where a lack of respect for her identity caused her to advocate for herself in the context of providing EOL care. Cassie's mother had an aggressive form of lung cancer that metastasized by the time doctors were able to detect its presence. Upon hearing this prognosis Cassie quickly decided to reduce the amount of college courses she was enrolled in and moved back into her mother's house to offer care full-time as her mother received in-home hospice. Although her older brothers were also living with their mother at the time, due to the Covid-19 pandemic Cassie was the only one who took her mother to and from doctors' appointments. Cassie took on this intense involvement in her mother's care without hesitation: “I have the capacity right now to be at everything and do everything. I don’t have to take off work to do this, I don’t have to take off class to do this. […] Plus, I just couldn’t imagine doing anything else, this is the most important person to me in the world.”

Cassie’s two older brothers were also living with their mom during this time and Cassie described how they responded negatively to her heavy involvement in their mother’s care. Namely, her brothers would push back on any of Cassie’s attempts to get help with tasks to keep the household running while their mom received in-home hospice. Throughout her interview Cassie spoke of sometimes ignoring their rebukes entirely, allowing her brothers’ positions to be explained by the confusion and intensity of witnessing their mother dying. At other times, Cassie fought back when her brothers refused to help. Importantly, Cassie detailed how her identity colored the caregiving negotiations that occurred between her and her brothers. She called upon two dimensions of her identity, her gender and age, to understand why she and her brothers disagreed about caregiving activities and to justify her self-advocacy in the face of those disagreements:

> Cassie: I think for the most part they were okay with [my level of involvement in caregiving], especially because it’s not like I was like, ‘Mom can only talk to me. I’m the only one that can do things.’ There were different times where I was tag teaming, like share this opportunity. I think that things in the house got stressful. Sometimes I’d ask my brothers ‘hey, can you do the dishes, can you mow the lawn today?’ And then, they would take that as their little sister bossing them around and be like, ‘I’m a grown man’, and I’d be like ‘yeah, but you also haven’t left your room in 24 hours and it’s full of Mountain Dew cans, so how well are you functioning right now?’ So, I could be a little harsh at times. We were all just scared and confused. I think that for me, it was easiest for them to start blaming me for things instead of letting themselves process.”

> LGK: How do you process that?
>
> Cassie: That's a really good question […]. That definitely got more intense as hospice care began. So my way of processing [is] I feel like I can understand it, I definitely hate it, and hate is a strong… whatever, I'm not going to be cliché right now.
>
> LGK: You can hate something; I hate a lot of things [laughs].
>
> Cassie: I definitely resent it because I know some of it stems from me being the youngest and the only girl. My life has always been like that, feeling like my brothers don't hear what I have to say. They don't really respect my opinion or think of me as an adult.

Due to restrictions from the Covid-19 pandemic, Cassie was the only caregiver privy to particular care activities such as attending doctors' appointments. Knowing this, Cassie made clear efforts to include her brothers in the care activities ("There were different times where I was tag teaming, like share this opportunity"). As care was enacted, Cassie indicated clear areas where her brothers *could* contribute to despite pandemic limitations, namely through help with chores to keep the household functioning while their mother received in-home hospice. However, her brothers openly disagreed with Cassie's requests for help. Cassie indicated her attempts at agency over caregiving by directly asking her brothers to be more involved in care (saying "I could be a little harsh at times."). Cassie stated that her care advocacy "got more intense as hospice care began" and that she held resentment toward her brother's for not respecting her opinions.

In expanding on why the interactions between her and her brothers occurred in the way they did, she explained that she believes her opinions were frequently dismissed because of age and gender dynamics. Ultimately Cassie believed that, because of her age and gender, her brothers did not respect her and that this was a longstanding dynamic at the core of their caregiving disagreements. Through this, Cassie revealed that issues of identity arise in context of EOL care. She further revealed that while some disagreements can be understood as reasonable given the macabre nature of caring for a dying loved one, disagreements consequential to a caregiver's sense of self and identity have the power to evoke self-advocacy and inspire feelings of resentment.

Catherine's father entered EOL care following a dementia diagnosis and, like many others diagnosed with dementia, Catherine's father exhibited physically aggressive behavior on multiple occasions. These uncharacteristic acts of aggression proved extremely difficult for Catherine and the family to understand. Catherine recalled one such instance of her father's aggression toward Catherine's mother, saying: "And he really was a nice person […]. He had another incident where he kind of actually almost like shoved my mom and she got really scared, because he was so not that person." Unfortunately, this incident was not isolated and Catherine recalled a more serious act of aggression between her father and mother:

> "It was an aggressive behavior—I was convinced he was okay, but my mom was [not]. When we talked to the doctor and everybody they said, well take him to the ER just to get [him checked out] because he apparently threatened my mom. Sort of grabbed her—not around the neck, but by the lapels and said, 'you're crazy,' and stuff. So they said take him to the ER to find out if he has a UTI or if anything is going on that would make this sudden change be happening. And they said also take him downtown where there's a psych ward because as soon as they heard 'attack'—and I'm going to use air quotes there—they thought psych ward. When I got up there I was like, he's fine. But I promised everybody I would take him to the ER and that was the beginning of the end honestly, because they gave him [benzodiazepine]. As far as we can tell, he had dementia with Lewy bodies. […] And with Lewy bodies, they can't have benzodiazepines and we found that out the hard way."

In framing her father’s multiple aggressive behavior incidents, Catherine took great care to state that this was not her father’s true nature. Emphasizing this, she indicated great skepticism of using the word “attack” and preferred to call it that only if using air quotes. This incident became the first to suggest that improper prescribing of benzodiazepines altered her father’s true nature. In another incident, described below, Catherine’s father is again prescribed benzodiazepines during a different stay at the hospital. This time, the medicine incapacitated her father thus altering his true nature, or identity, in a new way. Following this incident, Catherine took her father out of care against medical advice:

> “One time he was in the hospital for pain not too long ago. He was messing with his tractor all day because he was super active and then he had this horrible pain and they ended up admitting him to the hospital and they gave him [benzodiazepine] and it turned him into a completely different person. […] They decided to put him in the psych ward and within seven hours they had given him huge doses of those [benzodiazepines] and he was basically a non-person. And they wouldn’t let me in and when I went to get him I actually took him out against medical advice because they had drugged him up so much. It was really awful.”

Catherine demonstrated agency by correcting the care of medical professionals confidently and swiftly when she took her father out of the psych ward against medical advice. Taking a patient out of care against medical advice requires multiple confirmations of action, which Catherine did because their treatment of her father was causing him to act in ways not consistent with his identity as an unaggressive and active person. A surface level characterization of Catherine’s actions suggests that improper care motivated her agency through care correcting of medical professionals. However, deeper motivations can be gleaned from her multiple assertions that the aggressive and inactive behavior her father exhibited while on benzodiazepines were not characteristic of him. Thus, Catherine pulled her father out of care not only because of improper medication prescribed to him, but because this improper care altered her father's essential nature, or identity.

Objectivity

Respondents indicated that in the context of EOL creating a sense of objectivity, as related to garnering proper care for their dying loved one, was desirable—so desirable, that respondents engaged in advocacy in pursuit of objectivity. In this context objectivity is defined as the collective production of evidence in pursuit of freedom from bias. To be clear, the present analysis is *not* about whether objectivity was achieved. Instead, the present analysis seeks to demonstrate that objectivity was something caregivers valued so much that they took agentic steps to grasp at supposed objectivity. Sometimes, grasping at objectivity took the form of a respondent attempting to distance themselves from *sub*jectivity. In all instances, grasping at objectivity was indicated by respondents' (1) acknowledging potential bias that might negatively impact the quality of care their loved one received and (2) attempting to overcome this bias by supplementing its influence on care with diverse perspectives that might influence care differently. Potential bias came from respondents themselves (for example, when a respondent indicated their overwhelming emotions), as well as from other actors in the caregiving exchange (for example, a respondent who witnessed a dying person portraying their condition in an inaccurate way to medical professionals). The agentic moves made my respondents occurred frequently as corrective action (i.e. correcting someone's caregiving).

Brooke described being very close with her father, while she and her mother Janice shared a self-described “complicated” relationship. These dynamics intensified when Brooke became the primary caregiver first for her father, then for her mother during their EOL experience. While Brooke’s father was in hospice, she and Janice had frequently diverging wishes for her father’s care and her mother’s caregiving was frequently oppositional and erratic. After Brooke’s father died, Janice’s behavior became increasingly erratic causing Brooke to hire home health aides to look after her mom when she was at work. One day, aides noticed strange behavior from Janice and contacted Brooke to let her know that they were getting emergency services to pick Janice up. Brooke further recalled, “I get another call and it’s the EMS guys on the phone. They’re like, ‘Hey, is she usually able to verbally communicate?’ I’m like, ‘Yes.’ And they’re like, ‘Well, she’s not really communicating right now. So she’s awake, but she’s not communicating so we’re going to take her to [the local hospital]. You can meet us over there.’” Brooke left work for the hospital and met with Janice’s doctors upon arrival. Of her mother’s condition, Brooke recounted doctors saying:

> Brooke: ‘Well, she has this infection that’s so bad that she’s septic and it’s made her like this, and we’re getting the antibiotics in her, so we should start to see a change,’ and I was like, ‘Oh, okay.’ And I’ve just never seen her like that. I mean, well, I have, but it’s been a long time. So I stayed and then pretty soon they’re like, ‘We’re going to go ahead and get her up to a room,’ and I’m like, ‘Well, what—what tests have you done?’ It was like, ‘Well, we’ve just done the bloodwork and we know she’s septic, so that’s what this is.’ So we get up to the patient room and she’s still asleep and I left for the night and I’m coming back the next morning thinking—okay, I’ll hear her down the hall. She’ll be—
>
> LGK: Right, the antibiotics are working
>
> Brooke: Yeah! And I go in. Same. She’s just curled up in a ball. So, I wait. Wait for hours and finally someone comes through and I’m like, ‘What’s going on?’—

> 'Well, we thought the antibiotics would kick in, but we never know with sepsis and an older person like this it's probably just taking a longer time,' and it was weird, because they would bring a food tray in and just leave it in there. I'm like, 'Well, she's not going to eat that. I mean, she's asleep, but have you tried to give her anything? Has she awakened at all enough to give her something?'— 'Well, no. Nobody's been in here when she's been awake.' And I'm like, 'okay…' So a whole day went by and then we get to the next day and I'm sitting there—and I stayed the whole day that day, and she's awake but she's not talking. And she's looking at me, but I can't tell if she knows who I am. Then as the day went on, I start picking up on… this arm is doing a whole lot of stuff, but this arm isn't doing anything, and then I caught her kind of doing one of these [gesture of struggling to move]. And I was like, 'She can't move that side of her body, and she can't talk.'

Brooke only briefly accepted the doctor's confident assessment that her mother had sepsis that antibiotics would cure ("'we know she's septic so that's what this is'"). However, after days of observing her mother, Brooke realized that Janice's symptomology might be indicative of something more medically troubling. She questioned staff about whether they had seen her mother awake, to which they responded that no one had seen her mother awake. Medical staff continued to brush off Janice's symptomology as nothing serious and Brooke responded by asserting her agency over care by requiring doctors test to determine if a stroke occurred:

> When the doctor came through, I said 'did you guys do any tests to see if she had a stroke?' And they were like, 'Well, no. Why would we think that?' And I'm like, 'WELL… She's not talking. She's not moving this side of her body, I've noticed.' And they're like, 'Really? That side?' 'YEAH. She's not moving that side! She's doing this!' And they're like, 'And her eye's a little droopy on that side,' and they're like, 'I bet she's had a stroke.' I've had wonderful care there, so it was very strange. I think maybe it's the elderly thing, they just assumed this is just how she is even though I said that's not how she is. So, then I said, 'How do we know if she had a stroke?' 'Well, unfortunately at this point, there's nothing we can do because we would have needed the stroke machine within six hours.' And I'm like, 'Well, I still want to know if she's had a stroke.' And they were like 'well, we would have to do an MRI.' And I'm like, 'Well, I'm sorry, but I think you're going to have to.' Because for me, I—they kept asking me what I wanted

> to do with her. Like, what's our next step with her? And I'm like, "I don't know, because I don't know what's wrong."

Brooke's agency in the care context was exerted as she made marked and repeated attempts to get Janice an MRI to determine if she has had a stroke. Brooke alerted staff to Janice's symptomology which was met first with the medical staff's surprise ("'why would we think that?'") and then with their resignment ("'Well, unfortunately at this point, there's nothing we can do.'"). Despite medical staff's pointed attempts to deny Janice an MRI, Brooke would not take no for an answer and because of her advocacy, Janice eventually received an MRI. Brooke described the feelings of having to advocate for her mother's care: "I get mad sometimes when I think about the fact that I had to tell them that she had a stroke." In saying this, Brooke again confirmed the agency she exercised in the face of doctors' refusal to listen to her. Results of the MRI confirmed Brooke's suspicions and left her initially uncertain of her next steps in the caregiving process: "And then it turned out, no, she really is going to die in a few days, so… What do you do?"

Importantly, while caregiving for her father Brooke encountered a similar medical situation that would have been better understood if her father received medical imaging and Brooke drew upon this experience to guide her remaining caregiving activities for her mother. However, (and despite her mother's protests) Brooke did not advocate for her father's medical imaging. When asked about why Brooke pressed so hard for her mother's MRI despite not advocating for similar care for her father, she confided that she thought getting MRI results for her mother would help her avoid making selfish caregiving decisions for the parent she felt less connected to:

> "So, in all honesty, my life would be easier if she wasn't around. She was my mom. I loved her no matter what, and would take care of her no matter what, but I knew my life would be easier. And I didn't want that to be the reason that I just said, 'Oh, I'm power of attorney, and she's not going to survive so we're not going to do anything.' I needed more, and that's why with her I needed an MRI to tell me: '[Brooke], you've tried for years to help her. You are officially out of things you can do for her'. I needed that."

Here Brooke pointed to potential bias in her decision making given her complicated (i.e. fraught) relationship with her mother. Stating this further, Brooke said, "So, I was really trying not to let my personal feelings come into it. I mean, I'm sure they did to some degree, but I really tried." Brooke realized this great power and responsibility over her mother's life should not be wielded with her personal feelings as a guiding force. For that reason, Brooke "needed" an MRI to confirm that her mother was in such a state that ending medical intervention was objectively warranted.

Jenna used advocacy to check possible bias in the EOL caregiving she provided to her ex-sister-in-law, Hannah after a terminal ovarian cancer diagnosis. Alongside Hannah's two children, Jenna served as main caregiver and was responsible for many aspects of instrumental care as Hannah's son lived across the country. In addition, Jenna was uniquely suited to care for Hannah because Jenna's own sister had died of the same disease years prior. Jenna frequently drew upon what she deemed as the mistakes of caregiving for her sister, much of which she characterized as mistakes because those care decisions were tinged with Jenna's personal feelings. Holding the "mistakes" of caregiving for her sister became a driving force for Jenna's advocacy on Hannah's behalf when she noticed Hannah's son making care decisions based off what Jenna saw as the personal (subjective) emotions he was experiencing during his mother's dying process. In particular, Hannah’s son wanted his mother to travel out west to be with him and see the mountains, but Jenna was skeptical and thought this desire might be more for the son’s personal benefit than for Hannah’s.

To frame her advocacy for Hannah, Jenna told Hannah’s son of how she and another caregiving sister took the idea of travelling with their dying sister and frantically pursued it without paying attention to whether travelling was really what their dying sister wanted to do in her last days, saying: “I know because I had planned it with my sister. My other [caregiving] sister and I said to [our dying sister]: ‘Would you want to go mountains and ocean? We’ll take you and we’ll drive. Well, do you want to fly?’ I mean, all those things…” Upon reflecting on this, Jenna believed she and her caregiving sister pushed the idea of travelling too far and made it a proposition their dying sister could not deny even though there were signs that their dying sister did not want to spend her last days in this way: “ I feel— and I’m sure my sister felt the same way— If we could undo the expectations [we put] on her life, we would want to. [We’d ask] ‘would you want to do this? Is this where you’re at?’ Jenna further wishes she had asked what were her dying sister’s “expectations for herself. Not ones that we have for her.”

In explaining her motivations for this aspect of her caregiving Jenna recognized that the decisions she and her caregiving sister made were from their subjective feelings about their sister’s dying: “And it’s not that we even thought about, ‘well, you need to please us’ or anything like that. It wasn’t about that. It wasn’t about that. It was more of… gee… well-intentioned individuals maybe? But we weren’t necessarily considering where she was, or what she was necessarily feeling. [We didn’t] let it come from her.”

Here, Jenna points directly to how personal subjectivity colored her caregiving in a way that stifled the care recipient's ability to control what their last days looked like. Jenna held deep regret for these decisions and deemed them as mistakes she made in caregiving for her sister. Further, Jenna was committed to not making the same mistakes while caregiving for Hannah. Thus, when Jenna saw Hannah's son about to make the same "mistake" in caregiving for his mother, Jenna used advocacy (in the form of a conversation) to address the situation: "One time her son was talking in terms of just 'Oh you [Hannah] should come out to [western state]. You just come out to do this and just come out to visit there' […] Her son and I were alone together, and I said [to him], 'if she doesn't go it's not because she doesn't want to come with you. You don't see that's she seeing *your* vision in all of this." Jenna further explained to Hannah's son that he should consider the multiple dimensions that might make up Hannah's perspective:

> "It's maybe a combination of a couple things. What she's not showing you physically is that she physically she's not in the position to go [out west] maybe—or just not up for it. Not only that, it's psychologically. Psychologically, it takes a wear and tear as well as physical, and maybe she feels that this [where she is now] is all she knows right now—I mean, this is what she knows and that this is what she can control. And if she goes [out west] and she can't control things, you know? Sometimes people in Hannah's position… sometimes, that's everything for them. That they have a sense of control."

In a conversation with Hannah's son, Jenna directly addressed his subjectivity in trying to get his mother out west to see the mountains ("You don't see that's she seeing *your* vision in all of this."). Jenna crafted a compelling argument for why Hannah's son should consider the dimensionality of his mother's position, rather than focusing on his personal assumption that his mother should travel across the country to see the mountains he lived by in her final days (saying to him: "It's maybe a combination of a couple things.

What she's not showing you…"). While caregiving, Jenna took great care to be unbiased in her influence. The example above illustrates this commitment to distancing herself from subjectivity and the corresponding grasping at objectivity. The intense valuing of a more objective (and less subjective) approach to caregiving prompted Jenna to advocate for Hannah by urging other familial caregivers to adopt a similar approach.

Mandi was the primary caregiver for her father following a multitude of health issues that began with imbalanced sodium and electrolyte levels. Of her father's rapidly declining health Mandi said: "He was in intensive care for a week, trying to get everything stable. He had fluid in his lungs, he had congestive heart failure, he had stage 3 kidney disease. And from that time until his death, it was just chasing things. We never were able to get him healthy." There was great confusion over the cause of her father's descent into terminal illness and because of this Mandi attended many doctor's visits with her father to try and figure out what was happening with him.

Mandi described her father as a passive participant in these doctors' visits, while Mandi was more active and engaged. Of their differing interactional styles Mandi said: "I am a librarian by trade, so information is what I do—fact finding and putting it all together. […] I remember my father getting all [expression of being flustered when Mandi would ask questions]— 'cause he didn't question the doctor. I think that generation never challenged or questioned doctors." Mandi explained her caregiving approach to her father, saying: "Dad, I need to understand. I need to understand, so I'm going to ask questions." Here, Mandi began to indicate her interest in a more objective approach to navigating care by emphasizing her interest in collecting as much scientific information about her father's health and care as possible. This emphasis on scientific information was the most valuable element to help Mandi navigate caregiving for her father.

Initially, Mandi indicated that she would consider her father's sense of independence when attending doctors' visits. This meant that Mandi frequently allowed her father to direct the interaction:

> "When going to a doctor's appointments I would very very consciously try not to talk for him because he's his own person. He wasn't mentally incompetent at all, right up to the end. But there were times when he would either misremember or not quite understand the question that the doctor was asking, or the doctor would ask questions and he would say I'm fine. And I'd be like, but dad… you're not. Because he was [being] that man: I'm fine, I'm fine. And it's like, but you aren't."

As Mandi continued to tell her story, it became clear that allowing her father to set the tone of doctor's visits had its limits and there were times when Mandi enacted her agency in these contexts to ensure her father was receiving proper care:

> "Mandi: I will ask questions and challenge doctors because I need to understand. I just want to know. And I want to make sure you have all of your data because you have so many people that you're looking after. My parent is not going to stand out to you, so I just want to make sure you know [everything] and that's that.
>
> LGK: You mentioned letting your father maintain his independence but you also having this need to understand what's going on. So were there ever times that you had to choose between those two?
>
> Mandi: No, because in the larger picture it wasn't about—medically it wasn't about his dignity at that time. It was more—if it really didn't make any difference in the long run then, yes, I would let it go— but for the most part, I would say, 'Dad, I'm sorry', and then I would turn to the doctor and say, 'but you need to know that this happened…' Because they would ask him if he fell and he would say no. I would say, 'but dad, you did'. 'Oh, well, yeah'. And I said, 'because they need to know that Dad. They need to have all the facts that we can give them to make the best decisions for you."

Above, Mandi indicated that in instances where her father's preferred way of interacting with doctors meant he was concealing pertinent health information, she would intervene. At these times, Mandi would exert agency over the interaction, despite knowing that she was possibly compromising her father's sense of independence ("I would say, 'Dad, I'm sorry', and then I would turn to the doctor and say…"). Giving the rationale behind these acts of agency ("They need to have all the facts that we can give them to make the best decisions for you."), Mandi indicated a prioritization of "facts" and unfettered information sharing as the best course of receiving proper care for her father. In doing this, she intentionally moved away from more subjective motivations for how care should unfold (such as by considering her father's feelings/sense of independence as rationale enough for following his lead in the interaction) and moved toward a more objective basis for care (i.e. care founded on scientific information and "facts").

Justice

Although the established body of research on the prominent values concerning EOL did not reveal justice to be a prime concern of how death and dying is navigated, respondents in the current study did. Much of EOL care centralizes a dying persons' agency as the focus of medical and familial caregivers, such that caregivers protect the dying persons agency and in doing so forego their own. Given this, unexpectedly, the results below illustrated how caregivers of the dying valued justice so much that when an injustice was perceived it prompted agentic action from the caregiver. An adequate definition of justice in health at EOL is argued by some to be currently non-existent (Buchbinder 2018; Rhodes 2005). However, for the purposes of the current study drawing from both legal and bioethical definitions of justice adequately guides interpretation of the relevant results. Legally, justice is “premised on fundamental principles of equity, health justice requires that all persons have the same chance to be free from hazards that jeopardize health, fully participate in society, and access opportunity” (Benfer 2015). Layering a bioethical definition of justice adds two dimensions, one concerned with resource allocation that benefits the most disenfranchised called prioritarianism, and another concerned with resource allocation that “maximizes an outcome over a population” called utilitarianism (Rhodes 2005). Together, these definitions of health justice provide an adequate lens to view the issues of injustice that prompted respondents’ agentic action.

Teresa earned a masters in sociology where she focused her studies on death/dying and she was completing her hospice chaplain certification at the time of the interview. When asked how she chose that career path Teresa responded, “I just feel like no one should die alone […]. Just, it's the right thing to do. People shouldn't be alone in traumatic circumstances.” Even in introducing herself, Teresa began signaling her sense of what is right and just in EOL, namely that people should not die alone or in traumatic circumstances. From these educational and career experiences, Teresa was deeply familiar with what a good death should look like for her grandmother who was dying of advanced stage Alzheimer’s disease. The severity of Teresa’s grandmother’s illness became clear when she was no longer able to make routine associations such as how her saucer and teacup were to be used together. Her prognosis only worsened after suffering a series of mini-strokes and the family (Teresa, her mother, and aunts) quickly enrolled her in hospice care. Devastatingly, a horrific transition to hospice resulted in Teresa's grandmother dying in extreme pain:

> "Around, 12:30, the hospice nurse came, the intake nurse […]. About an hour and a half later my grandma started freaking out, she said she couldn't breathe. She was gasping for air. She was in pain. She was asking for help, asking what was going on. […] What her daughters did was start to call the hospice company desperately because they didn't want their mom to die in a hospital. Their dream was for her to die peacefully at home. So […] they stayed with her and waited four and a half hours for hospice to show up, which the lady on the phone promised them multiple times as they called that someone was coming. And no one ever showed up. So they kept calling and calling and the lady kept saying 'the guy is on the road, he is trying to be there as fast as he can.' And he ended up showing up—I think she died around 5:30— and he showed up ten minutes later. And unfortunately the doctor was out on a date with her husband and didn't answer her phone."

Describing the effect of this miscarriage of care, Teresa said "It was awful because of my experience working at the hospital and my studying of death education and care and my understanding of what hospice is supposed to do. The good death—that's I wanted for my grandma and not to be able to provide that is heartbreaking." When asked why she thought her grandmother's death occurred in the way it did, Teresa made clear that she believed her grandmother's exclusion from a pain-free death was the direct result of medical injustices of negligent care and systemic failings:

> "Well, I can tell you what I think. Safeguards need to be in place for it to go better. So, if the boarding care facility had had their act together and had known what resources they had and had communicated to the owner [things might have been different]. There was some act of miscommunication there. There was a lack of communication on how to reach [the hospice nurse] or what her responsibility was in the situation. I think everyone just kind of pushed off responsibility in this case. Thirdly, the hospice company not giving my family the option of maybe we should just take my grandmother to the hospital where they would have put her on comfort care within an hour instead of hours waiting and never showing up. I don't know, I think the system broke down in various ways."

Teresa then demonstrated her valuing of justice in matters of EOL by imagining changes to the dying industry that would prevent injustices like the ones Teresa's grandmother (extending to Teresa herself) experienced, described below. She further demonstrated this value by asking if I knew of any avenues she could use to find recourse for the injustice:

> "Like I said, having the route to try to prevent that from happening again, and I don't know if there is a national hospice association or a board that oversees or what. […] I feel like a way in which we can improve hospice is maybe if a hospice company was involved in any way, the family needs to be sent a letter and a family needs to get feedback to some sort of overarching, overseeing agency. There should be some sort of way to make sure that quality care is being provided. Is there one?"

Collectively, Teresa's quotes illustrate an acute awareness of the form just treatment, and thus justice in EOL itself, should take. Teresa's grandmother was denied a good death due to a calamity of medical injustices including absentee doctors, poor or non-existent doctor communication, and general systemic breakdown. Teresa experienced all of this as traumatic, again highlighting a valuing of justice in the context of EOL care, a value so strongly held that months after her grandmother's death Teresa was actively seeking recourse.

Brandon was the primary caregiver for his grandmother who was enrolled in hospice after her health deteriorated from a multitude of conditions including heart disease, diabetes, chronic obstructive pulmonary disease, and issues with kidney functioning. Brandon's grandmother was receiving hospice in a nursing facility while Brandon maintained full-time employment in the Information Technology field. Before this career, Brandon worked for years as a nurse which made him intimately familiar with issues of adequate facility and EOL care and how that varied by a given facility's access to resources:

> "Now, in-between working at hospitals, I worked as a nurse's aide, and I also worked as a sitter in different nursing homes around the city. I worked at a nursing home called [facility in a wealthy suburb]. That nursing home looks like a hotel. […] It's amazing. I walked in there and I was just like, 'Holy shit! This is the most amazing nursing home I've ever seen!' I've also been in other nursing homes where it was just like, damn. I would rather my parents live with me than here. And that is really those things where economically—like the reality of the way it is, is that the money is not spread evenly in this country."

In his interview, Brandon explained that he chose facility care for his grandmother because it was important for him to be able to keep working in his career full-time. In the quote above, he illustrated that his strong preference for facility care had limits, such as if the only financially feasible facility was one with limited resources ("damn. I would rather my parents live with me than here"). Summarizing the lessons learned from his time in healthcare Brandon stated, "I think the biggest thing for me is that I learned that, in my time in healthcare that there is a huge disparity in care based on how much money you have." Brandon was not the only one in his family privy to this understanding of disparities in EOL healthcare options in their area. Revealing this, Brandon described a long running family joke about a local nursing facility with a reputation for dilapidated accommodations and inadequate care: "There is a joke in my family about a nursing home called [Woodgrove Nursing]. It has a reputation for being a very poor nursing home. […] So the joke has always been you know, 'Yeah, when you guys get old, I'mma put you in [Woodgrove] and leave you there.'" Brandon and his family joke about Woodgrove as if it would be a form of punishment to receive care from this facility. By satirizing Woodgrove, their local nursing facility i.e. the facility most accessible to them, the family makes the injustice inherent in inequitable distribution of economic resources apparent.

With this understanding, Brandon enacted agency over his grandmothers care accordingly by ensuring that she would never be placed in a facility like Woodgrove. Brandon achieved this through a program that took ownership of his grandmother's assets to pay for care:

> "Most [nursing facilities] that are catered towards quality-of-life stuff, they're built in rich neighborhoods. So, in that respect, people that need end of life care, if they don't have the money to afford or the means to afford nicer places, they're gonna end up going to [Woodgrove] cause that's all they can afford. […] I never worked at [Woodgrove], but I've been in it visiting other people; there is no way in hell. So, there are huge differences in the care you get depending on how much money you have. My grandma […] she's on this program where basically, the federal government takes all of her assets. It's like, your house belongs to us. Your–if you have a car—all your shit belongs to us. We will take care of you until you die. When you'd die, then we'll take all of your stuff and sell it and that's how we'll get reimbursed."

Brandon was the only respondent interviewed that used such a program to ensure his grandmothers access to a particular type of nursing facility. Use of this program effectively severed his access to his grandmother's many assets upon her death, a sacrifice Brandon welcomed in order to place his grandmother in a facility not negatively impacted by issues of structural disadvantage. This agentic decision-making that eliminated his grandmother's need to receive care in the local disenfranchised care facility highlighted the existence of injustice in seeking end-of-life care, and the extreme measures taken to avoid confronting such injustices.

Amira, a full-time university student, had EOL caregiving thrust upon her after her father suffered a suspected stroke at work states away from where Amira lived. In time, Amira would learn that her father had been diagnosed with terminal lung cancer and was paying out-of-pocket for experimental treatments up until the time of his stroke. Incapacitated by the stroke (and per state laws) Amira became her father's power-of-attorney (POA) while he was living, and executor of his estate upon his death two weeks later. Amira was forced to use her POA rights to make EOL decisions for her father as he did not have a written will, and upon his death family tensions emerged:

> "So they call me while I was at one of my classes, on like a Thursday. It was just the hospital asking me if they could remove his breathing tube. I said yes and then he was able to breathe on his own for about 20 more hours. So that Friday is when he passed, finally. And then that's when things started getting really weird with my family relations. That night my mom, my brother, my aunt, uncle and cousin and grandparents all went back to my dad's house. Everyone was going to leave in the morning, but they all went back to go to bed and just process.
>
> My dad was making a lot of money because he was a really high powered [executive] so he had a lot of really expensive things in this house. And my mom and brother went to bed and then my mom said that she had heard shuffling downstairs, but she didn't know what it was. My uncle had went out and gotten a U-Haul and started packing all of my dad's stuff into the U-Haul. But the frustrating thing was they weren't taking photo albums or his degrees or anything like that, they were taking expensive bottles of wine, paintings he had gotten in Italy, wood carvings from Africa—things that had really intense monetary value. […] My grandma at one point asked, she was like 'can we take the TVs?' And my uncle was like 'that would have to be later because we have to dismount them' blah blah blah. My mom was like this is weird. This is a weird situation."

Upon the death of Amira's father, Amira's grandmother and uncle begin taking monetarily valuable items from the house that Amira later speculated was so they could be sold for money. Amira described this behavior as "weird" in several points of her interview. By labelling the action as such, Amira began to signal an interpretation of events as possibly out of the norm, or unjust. She emphasized this point by comparing her father's possessions with monetary value that were taken (expensive bottles of wine, paintings, wood carvings, TVs) with sentimental possessions with no monetary value that were left with the estate (photo albums, degrees). Amira further described this distinction in what was taken without permission and what was not as “frustrating” and together these findings provided commentary on what Amira believed should (and should not) be valued in matters of EOL such as settling an estate.

Throughout the settling of the estate, Amira’s grandmother and uncle attempted to take the executor position from her, first by trying a legal route: “Since he lived in [southern state] everything is still in [southern state], which means I’m his next of kin. I’m the administrator of his estate which rocked my grandparent’s world. My aunt and uncle hired a lawyer to try to see if they can squeeze me out of it, I guess. But the lawyer said that’s not really how it works. So they just started working with a lawyer on their own.” When this legal attempt proved unfruitful, Amira’s family appealed to her and her mother’s emotions to have Amira step down as executor: “My uncle called my mom one night in the last interaction I had with my uncle. Where he called my mom and was yelling at her and was like, ‘you have no idea how intense it’s all going to be! Tell Amira to give up her rights to be the administrator because she’s not going to be able to handle it!’” In response, Amira (along with the help of her mother) hired an estate lawyer to help her assert her rights and she was able to settle the estate more effectively from that point on.

Through a pattern of behavior, beginning with renting a U-Haul the evening of her father’s death up to an emotionally charged call for relinquishing her rights, Amira recognized the different values underpinning her and her family’s desires for settling her father's estate. Not only did her grandmother and uncle eschew legal authority, but they also attempted emotional manipulation of the situation, and assigned "weird" value to some of her father's possessions over others. Noticing these unjust actions in a time where Amira believed her legal rights should have been respected and that the sentimental value of her father's possessions should have been treasured, Amira enacted agency accordingly by not giving in to her family's demands and protecting that agency with the help of a hired estate attorney.

Discussion

Current understanding of how death and dying is navigated centralizes the viewpoint of dying persons. Specifically, current research has explored the agency of (or on behalf of) dying persons in various strata of social life, but has yet to establish how family caregivers of the dying— key actors in the dying process— enact agency in EOL contexts. Further, looking to research on social values yields an incomplete understanding of the role of familial caregivers as the values explored centralize the health and well-being of the dying person to the exclusion of all others (or rendering family caregivers as an afterthought at best). While focusing on dying persons can be sensibly justified for reasons of improving dying persons' access to rights and exercises of agency, this singularity of focus has obscured understanding of how and why agency of familial caregivers of the dying is enacted. Family caregivers are prominent actors in the dying process and, aside from possessing *their own* personhood for which agentic capacity should be understood and promoted, their agentic power holds direct implications for their ability to provide effective care for a dying loved one.

To address this deficit in our understanding of EOL matters, in-depth interviews with 25 familial caregivers of a dying loved one yielded insight into two distinct questions: (1) how do caregivers of the dying explain their choice to exercise agency in the care context? And (2) what social values are reflected in the exercises of agency performed by caregivers of the dying? Responses to these questions reveal that familial caregivers of the dying use *mortality beliefs* justify their participation in agentic action while caregiving. Mortality beliefs is a new concept born of the current research that describes distinct values of identity, objectivity, and justice.

The accomplishments of the present study are threefold. First, the findings establish that although caregiving for a dying loved one is a largely passive project because of the centralization of the dying patient's needs, familial caregivers *do* find occasion to exert their own agentic power over the care context. While previous research on physicians' perspectives on caregiver agency characterize their agentic power as "weak and vulnerable" (Buscarolli and Mikko 2021), respondents in the current study illustrate a multitude of motivations behind their agentic action. Further, research on advocacy as agency might predict that agentic action is only undertaken when it stands to benefit dying persons. This exact focus of agentic action can be seen many times over in advocacy for patients' rights to die as well as in small scale acts of agency such as through individuals' legal EOL planning (Buchbinder 2019). However, results of the current study complicate this singular focus. Namely, the data present no such patterning of who enacting a mortality belief stood to benefit. Said differently, respondents in the current study sometimes advocated for protecting their own identity and sometimes for the identity of the dying person. Sometimes advocated for objectivity that would benefit their own peace of mind and sometimes when it would benefit the quality of care a loved one received. And sometimes advocated for justice for themselves or for their loved one. Thus, the unifying thread of the present data is the mortality belief itself making the concept a durable way to understand agentic action of caregivers in matters of EOL.

Secondly, the present study vividly accounts for the distinct values that agentic actions reflect. Through their agentic action in service of a mortality belief, respondents underscore what it is that they value in their experience. The existence of identity and objectivity mortality beliefs in the ethos of caregiving is not entirely surprising. Regarding identity, modern western values of individualism reign supreme and this is seen in various EOL tasks such as care planning. Specifically, community dwelling adults' decision making is motivated by a need for maintaining personal autonomy to every extent possible at EOL (Bullock 2011). Even when autonomy is gravely compromised in instances of bodily decay, the identity of the care receiver is protected through the actions of the caregiver (Isaksen 2002). In these cases, it is common practice for a child caregiving for a parent to reaffirm power dynamics (specifically the parent's advantaged power position) in their relationship to preserve the parent's sense of identity when bodily decay occurs (Isaksen 2002). Unpredicted by previous research is how respondents in the current study placed such great value on the identity mortality belief that it prompted them not only to exert agency to protect the dying person's identity, but also *to protect their own sense of personal identity.* Regarding objectivity, medical doctors (who can be understood as one kind of caregiver on a team of caregivers at EOL) highly value objectivity in their medical and caregiving practice (Livne 2019; Timmermans 2006). Thus, although family caregivers likely hold different knowledge bases and levels of medical authority than doctors, it is possible that the pervasive valuing of objectivity among medical caregivers easily extends to the values held by family caregivers.

Notably, a clean mapping of previous research on health and EOL values onto the experience of familial caregivers of the dying did not occur. First, although extensive attention has been paid to the economic values that are reflected in a multitude of EOL activities, such as the secondary market for buying and selling life insurance policies (Quinn 2008) or the moralization of medication scarcity in hospice (Livne 2019), a corresponding emphasis on economic values was not expressed among respondents in the current study. Instead, the singular mention of economic concerns that related to agency (see quotations from Brandon) were indicative of valuing justice more than valuing economics. This highlights the present study's second notable departure from the expectations of previous research. Respondents illustrated a clear understanding of (in)justice in the EOL context. Issues of injustice awareness and EOL dominate in macro-level conceptualizations of agency, reflected poignantly on research on health social movements (Best 2012). Until now, issues of acutely understood injustice are rarely (if ever) represented in micro-level examinations of caregiver EOL agency. Improper carriage of justice is not easily ignored as evidenced by immense large-scale social effort exerted to prevent injustice, as is seen in social movements promoting equitable EOL care access (Buchbinder 2018). Thus, it is of little surprise that ensuring justice at EOL was of main concern to familial caregivers. While the role of injustice in inspiring agentic action from familial caregivers may come as no surprise, it possibly uncovers a pernicious element of caregiver agency—that something as consequential as injustice must be at stake for a familial caregiver's agentic action to occur. Moreover, similar sentiment could be said of the other mortality beliefs of objectivity and identity that reflect deeply held higher-order social values.

Regardless of whether mortality belief findings are to be interpreted optimistically or not, the findings establish a clear relationship between values and agentic action which constitutes the third major accomplishment of the present research. Sociology's investment in values as a worthy area of inquiry has been variable at best. When sociologists do engage with values, they tend to do so in passing and simply "tack on the phrase 'norms and values' to explanations of human behavior to connote the taken-for-granted process through which social structures regulate the actions of individuals" (Hitlin and Liliavin 2004, p. 359). Minimizing or ignoring values fails to take advantage of an element of social life that functions "at the levels of individuals, institutions, and entire societies" (Hitlin and Liliavin 2004). The present results help bolster the claim that explicit analysis of values, described here as mortality beliefs, hold immense relevance to the sociology of death and dying by connecting values directly to agency. Among caregivers of the dying, values help explain why agency occurs in a context where a non-dying person's ability to claim agency is often thought of as of lesser importance when compared to the dying person.

Chapter 5. Conclusion

Dying is one of the few universal social experiences humans face and despite this ubiquity we lack deep understanding of how the contours of dying are navigated. While the major task of sociological research, health social movements, and the actions of medical professionals has focused on improving the options available to and experiences of dying persons (a decidedly worthy cause) there has been considerably less focus on how the experience unfolds for familial caregivers of the dying. Inspired by this, my dissertation sought to remedy this shortcoming by exhaustively interrogating agency as it does and does not manifest in the experience of family members who give care to their dying loved one.

In empirical chapter one I sought an understanding of how family caregivers of the dying viewed their role in the dying process and where the messages of how to behave within their role came from. All respondents adhered largely to one of three caregiver archetypes: the unbiased ally, the deferential supporter, or the unbewitting bystander. These archetypes all indicated some degree of the caregiver's compliance with an outside guiding force and most frequently that guiding force emanated from the dying person's wishes for their EOL experience. These archetypes of compliance left caregivers with little guidance for understanding the agency that could have be found in their own experience of providing care to the dying. As a result, for much of the caregiving experience caregivers did what their chosen archetype outlined and they did not claim agency over the care context or their experience.

In empirical chapter two I sought understanding of the processes beyond caregiver compliance archetypes that informed the subdued agency of familial caregivers of the dying. I found that corrections of care improprieties did occur, but that correction was subtle in nature. Despite noticing clear care improprieties, such as improper medication prescribing or use, respondents did not respond in kind by clearly addressing misgivings in care. Further, no care actor was immune by virtue of professional authority or standing within the family as respondents corrected medical professionals, lateral family members, and lineal family members. Although the intended outcome of the correction differed by who was being corrected, considerations of family served as the driving force for why subtle correction (rather than more overt forms) was enacted. Thus, familial caregivers of the dying illustrated a desire to prioritize and protect family dynamics and this resulted in the constrained influence they exerted on the care context, even when their influence stood to remedy an objective misgiving.

Finally, in empirical chapter three I sought to interrogate the motivations behind the limited instances in which caregivers exerted clear, unwavering, and decisive agency over the care context. Asking, ‘what must be at stake for a caregiver of the dying to *finally* claim agency over their caregiving experience?’ I found the answer in mortality beliefs which encompassed the values so strongly held by caregivers that it inspired agentic action. Mortality beliefs reflected respondents’ deep investment in identity preservation, objectivity seeking, and exacting justice. Furthermore, I was surprised by who respondents leveraged mortality beliefs for the benefit of. Empirical chapters one and two would have led me to the predication that it was for the benefit of dying persons, as most of the efforts of caregiving attempt to do. However, mortality beliefs were durable enough to inspire not only agentic action to benefit dying persons, but agentic action *for the benefit of the caregiver themselves*. Together, these findings confirmed for me that indeed, agency is difficult to exercise in the context of caregiving for a dying loved one. So difficult in fact that for the occasion of an agentic action to occur, deeply held beliefs about identity, objectivity, and justice must be weighing in the balance.

Limitations and Future Directions

As all studies are, the present research is not without limitations. The first limitation is perhaps inherent in the very thing that inspired this dissertation: the competing ubiquity and taboo of death. Although we all experience dying one way or another, it is not an element of our social or personal lives that we are primed to engage with well. Thus, when recruiting participants there was likely an element of selection into the study that occurred. All of my respondents enthusiastic in sharing the intimate details of some of the most harrowing experiences of their lives. This willingness, and the language (and emotional literacy) to communicate complex and taboo subject matter with a stranger, likely contributed to sample selection in some way that I may never understand the full nature of. Future research should aim to account for more diverse perspectives on EOL caregiving namely through samples of those less likely to find death and dying as tolerable (and even enjoyable, as some of my respondent described) topics of conversation. Research participants of this kind may new yield insight into how agency is exercised differently when it must contend more poignantly with social taboos.

Secondly, hospice is an overwhelmingly white venture, at least where hospice recipients are concerned. More than eighty percent of hospice recipients are white (Vossel 2021), and due to familial racial hegemony it is likely that a similar percentage of family caregivers of the dying are white. Although every effort was made to increase the racial and ethnic diversity of my sample, fifteen of the twenty-five respondents self-identified as non-Hispanic white. This limits the applicability of my data in key ways as race is consequential to what healthcare options are available to individuals, their trust in those options, their expectations of family support in health crises, and beyond. As a result, the findings of this dissertation should be understood through the racial/ethnic lens of a sample that is largely white. Further research should seek racially and ethnically diverse samples of EOL caregivers to explore how the experience unfolds differently from what is presented here. Because hospice is an industry that caters primarily to white care recipients, inquiry of this kind should consider expanding beyond the hospice context.

Finally, this dissertation speaks well to the experiences of caregivers of the dying when the timing of death is *known* and *proximate*. However, this dissertation cannot speak to experiences when the timing of death uncertain. This distinction is of paramount importance in a national and global historical context of pandemic, genocide, and rampant police brutality. Within these contexts there are innumerable influences on whether and how actors may exert agency over (possible) death. As this dissertation explores, individual agency is situated within structures and institutions that have immeasurable impact agentic action, particularly when those structures and institutions place themselves in direct opposition to individual agency over life itself. Thus, although death itself is ubiquitous, the findings of this dissertation should be understood as finite in their applicability to the modern ills facing humanity. Future research should account for the multiplicativity of how EOL comes about for an individual and their family. By investigating this we stand to better comprehend how these historical contexts are reckoned with in ways that are consequential to individuals and institutions.

Final Thoughts

To be born means that one also must die. It is with this understanding, and the humility therein, that I have approached this dissertation research. In the dozens of hours spent interviewing respondents for this project, I believe that understanding and humility also undergirded their approach to caregiving. All respondents wished for a “good death” for their loved and this intense wish left respondents open to outside influences on what care for their loved one “should” look like. None of my respondents thought they individually held the secret to how care should be executed. Thus, caregivers sought diverse perspectives on how to care. This humility was found in their overall caregiving strategy, fitting somewhere into the three-fold caregiver typology where all options exhibited some form of compliance with outside forces, albeit to varying degrees. Then, even in the face of clear care improprieties that impacted the quality care they so desired for their loved ones, caregivers offered only subtle corrections in response. Humility in this context may have taken the form of recognizing that caregiving should not be done alone, and that family offers an anchor point from which to navigate care during a time of acute normlessness. Thus, respondents did the delicate balancing of providing quality care with protecting family dynamics.

However, these surrenders to outside forces did not hold for all circumstances of care. Exerting agentic power in care arose when mortality beliefs were brought into question for either the dying person or for the caregiver themself. This indicated that although much of the minutia of caregiving is an exercise in compliance, there exists a boundary in EOL care between when compromising individual agency (willingly or unwillingly) is and is not acceptable. Empirical chapters one and two establish the potential gains one receives from forgoing use of their individual agentic power. It may offer a template for how to navigate care or it may serve as a way to protect desirable family dynamics. However, as empirical chapter three establishes, forgoing agency in the EOL context leaves one vulnerable to violation of deeply held mortality beliefs that can only be protected through agentic action. While much of the task of sociology is found in service of understanding and increasing individuals' agentic power, this dissertation's presentation of the simultaneous positive and negative dimensionality of agency should be cause for reflection.

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Appendix A. Interview Guide

Ohio End-of-Life Study

Guide for interview with family member of dying person

NOTE: “Other family member” refers to a family member that is not the dying person. “Family member” refers to the dying person. During the interview, “Family member” will be replaced with person’s name to prevent confusion.

Opening Questions: Tell me about your person, what were/are they like? When did their health start declining?

The Care Plan:

1. How long has your family member been in hospice care?
2. What was the diagnosis of your family member upon entering hospice care?
3. How did your family decide between receiving care in the home versus in a facility?
4. Hospice provides many different aspects and forms of care. Can you describe the care your family member currently receiving?
5. What family members care for your family member? What are the titles and roles of medical professionals that care for them?

6. Are you happy with the care plan? What do you wish was different? What do you not want to change?
7. How has your care plan changed over time?
    a. Do you think those changes have been good/bad/or both? Why?
8. Do you ever disagree with a part of the care plan? Why? How do you deal with this?
9. Have you ever had to advocate for a change in the plan? How did you do this? Did you have any allies in this? How did you feel during this time?
10. What does the future of the care plan look like? Are you happy with that?
11. Is there anyone you wish was more involved in the care plan? Less?
    a. How do you feel about their level of involvement?

Actors in the dying process:

<u>Medical Professionals</u>

1. What medical professionals are a part of the care plan? What do they do to care for your family member?
    a. How do you feel about their role in care?
    b. When are times you feel particularly supported by them?
    c. When are times you feel particularly unsupported by them?

2. For those in facilities: Is anyone else in the facility a part of the care plan? What do they do to care for your family member?
3. What sorts of questions or concerns do you turn to [medical professionals]* for? Why?
    a. How does their response to your concern make you feel?
4. What sorts of questions or discussions do you NOT turn to [medical professionals]* for? Why?
    a. How do you imagine they would respond to your concern?
5. Is there any information you keep/refrain from telling medical professionals? Why?
    a. What would happen if you told them this information?

Family Members

1. What other family members are a part of the care plan? What do they do to care for your family member?
    a. When are times you feel particularly supported by them?
    b. When are times you feel particularly unsupported by them?
2. What sorts of questions or concerns do you turn to [other family member/family member]* for? Why?
    a. How does their response to your concern make you feel?

3. What sorts of questions or discussions do you NOT turn to [other family member/dying family member]* for? Why?
    a. How do you imagine they would respond to your concern?
4. Is there any information you keep/refrain from telling [other family members/family member]? Why?
    a. What would happen if you told them this information?
5. Who has more bearing on what your care plan looks like, medical professionals, you, other family members, or your family member? Why is that so?
    a. Are you happy with this?
    b. Was this always the case?
6. Who do you celebrate good news with? Why?

*tailor language for any and all persons indicated by R

Technology:

Sometimes we think of technology as a highly developed tool, like machines for medical scans, but I like to think of technology also in more mundane terms, like blood pressure cuffs and thermometers.

1. Do you ever encounter technology as part of your family member’s care? What technology is this?
2. Has there ever been a time when you did not understand test results or procedures of care your family member was receiving?

    a. How did not understanding this make you feel?
    b. Did you get clarification on what was happening? How?

3. Do you think more technology should be used in your family member's care? Why?
4. Is there anything comforting about the use of technology in your family member's care? Why? Which technologies in particular are you thinking of?
5. Is there anything concerning about the use of technology in your family member's care? Why? Which technologies in particular are you thinking of?

Dying:

1. How did you find out your family member was dying? beginning hospice?
    a. How did you feel upon hearing this news?
    b. What was upsetting about finding this out?
    c. What was comforting about hearing this news?
2. How do you define dying?
3. What were you told to expect upon starting hospice care? Who told you?
4. How has your experience matched up with what you expected of Hospice care?
5. What has been the hardest part of moving into end-of-life care?

6. What has been the easiest part of moving into end-of-life care?
7. Who do you think is qualified to talk with you about [/give you advice about] the dying process? Why? What do they tell you?
   a. Who do you like talk about end-of-life with? Why?
   b. Who do you not like talking about end-of-life with? Why?
8. What role have other family members played in the dying process? Physically, spiritually, emotional, practically?
9. What role have medical professionals played in the dying process? What role have religious officials played in the dying process? Physically, spiritually, emotional, practically?
10. Who do you talk about dying/death with? [probe about family, friends, medical professionals, clergy] What do these conversations look like?
    a. Has anyone ever said anything that has upset you in these conversations? What did they say and why was it upsetting?
    b. Has anyone ever said anything that "stuck with you" in these conversations? What was it and why did it stick with you?
    c. Has anyone said anything useful to you in these conversations? What was it and why was it useful?

11. Have you ever read anything about dying? Why/why not? If yes, what did you learn from this?
    a. How much of what you read do you feel has applied to your situation? Give examples?
12. What did you wish you had known about the dying process?
13. If a close friend found out their family member was dying, what sort of information would you share with them, if any?

Resources:

Resources can take many forms, like financial, time, emotional, having knowledge, etc.

1. What resources are most important in how you care for your family member? Why?
    a. Do you think your caretakers would agree with your answer? Why or why not?
2. What resources are the least important in how you care for your family member? Why?
    a. Do you think your caretakers would agree with your answer? Why or why not?
3. Do you think you have the necessary resources to care for your family member? Why?
    a. How do you feel about having/not having the resources?

b. Does your family member know about you having/not having the necessary resources?

c. What would happen if your family member knew you did/did not have those resources?