Caring at the End:  
Tensions in the Organization of Hospice Work

Book Prospectus

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Concept

Caring at the End documents the everyday work lives of hospice care providers, extending analysis out several domains of sociological concern: workers’ sense of self; paths into hospice work; meaningful work experiences; the routinization of caring for the dying; spirituality; alternative constructions of death and dying; stigma related to handling dying bodies; workplace inequality; emotions and emotional labor; and, constraints on the administration of care. Using data from ethnographic fieldwork, semi-structured interviews, and a survey of hospice workers, Caring at the End argues that hospice workers navigate three main tensions between their own needs and the needs of others; commitment to the hospice philosophy and change to the organization of hospice work; and a desire to go mainstream while still adhering to alternative beliefs about death and dying.

Caring at the End posits that hospice workers respond to these tensions by forming a unique subcultural group, and through this subculture they are able to develop strong identities, create narratives about the significance and ultimate meaning of the work, transform dying into a mundane event, and deal with the reactions of stigma from others. However, the insularity of the hospice subculture also results in problematic team dynamics and individualistic responses to structural pressures. The book concludes by discussing how future structural changes to the healthcare system are likely to exacerbate the difficulties embedded in hospice subcultures, while also weakening many of the coping strategies developed by this group. The future of hospice work will likely shift to make the work more difficult and less rewarding, but through a more nuanced understanding of the experiences of hospice workers, it may be possible to intervene and ensure the continued commitment of those who care for our dying. This will be increasingly important as the American population ages and the need for end-of-life care increases.

Overview of Findings and Significance

The main findings of Caring at the End center around three tensions in hospice work, each of which are woven into the empirical chapters and fully elaborated in the introduction and conclusion. The first tension is between hospice workers’ commitment to their work and hospice
organizational changes that make this commitment difficult to sustain. This tension is most explicitly illustrated in Chapter 2- Finding Yourself (Working) in Hospice; Chapter 3- Life in Hospice; and Chapter 6- Constraints on Caring. In each of these chapters, Caring at the End uses workers’ own comments to show their high levels of commitment to the philosophy of hospice: many report that they have “found themselves” through their hospice work, while others emphasize that hospice is a calling, made worthwhile by emotional connections to patients and their family members. However, changes in the organization of hospice work—especially due to changes in Medicare requirements—threaten to reduce the amount of time hospice workers have to make meaningful emotional connections with their charges. Much to their frustration, hospice workers now spend more time than ever on administrative work, documentation, and meetings. These structural changes impose constraints that workers have, thus far, responded to in individualistic ways.

The second tension presented in Caring at the End is between workers’ own self-care needs and their work of tending to the needs of others. Frequently the behaviors thought to best support patients are in direct contradiction to the behaviors that workers claim are necessary for maintaining healthy distance. For instance, many hospice nurses report that even when are on vacation or otherwise not on duty, they request that their co-workers call them if the health of a patient changes. On one hand, this request ensured that patients had consistent, involved care. On the other hand, many hospice staff made it clear that time away from work was essential to keeping up the emotional energy necessary for the work. Many nurses were reluctant to take that time away. The needs of the patients were held in tension with the workers’ needs for breaks. This tension is illustrated in Chapter 3- Life in Hospice, Chapter 5- Emotional Divisions of Labor, and Chapter 6- Constraints on Caring.

The third tension within hospice is between workers’ desire to make hospice services more mainstream, and workers’ knowledge that some of their practices and beliefs run counter to that of the general public. On a daily basis, hospice workers manage their presentations of self and information about the work they do in order to encourage acceptance and use of hospice, carefully negotiating the tension between assimilation and difference. This is most apparent in the meanings they construct about death: death is beautiful; it is a gift to be near those at the end-of-life; death is similar to birth; and working with the dying is not inherently sad. While workers’ deep commitment to the philosophy of hospice includes increasing awareness about hospice as an option, they also know that their alternative beliefs about death are not always accepted by outsiders. This tension is shown primarily in Chapter 4- Death in Hospice.

Taking these three tensions into consideration, Chapter 7- Conclusion argues that hospice workers are most successful navigating tensions when they have strong relationships with one another and a full commitment to the philosophical underpinnings of hospice. In effect, hospice workers form a subcultural group which allows them to adjust their practice alongside organizational changes, balance self care with the care of others, and properly negotiate the mainstreaming of hospice with their alternative belief systems about death and dying. Caring at the End posits that this subculture is essential for workers’ ability to perform high quality care, but also suggests that if any of the above tensions become unbalanced, the subcultural group is challenged. Caring at the End concludes by discussing the future of hospice, expectations about
the subcultural group, and showing how hospice workers’ struggles represent the struggles of caring work more generally.

Chapter Summaries

Chapter 1. Introduction: Caring at the End

The Introduction will provide context for the subsequent chapters through a short review of the history of hospice, including the transition from hospice as a grassroots alternative to conventional care to hospice as part of the conventional care system, and hospices’ alternative orientation toward death and dying. It will then briefly discuss literature on caring workers’ sense of self, caring labor, and emotions at work. These two sections will be brief, seeking to ground my discussion of the three tensions discussed in the empirical chapters: commitment during change; self and other care; and assimilation or difference. I will then give an overview of the study design, highlighting my use of mixed methods, including participant observation, interviews, and a survey of hospice workers (a more elaborated discussion of the study design will be presented in the methodological appendix). The final section of the introduction will summarize each empirical chapter in a single paragraph, weaving in the argument that hospice workers form a subcultural group in order to deal with tensions in the work.

Chapter 2. Finding Yourself (Working) in Hospice: Unconventional Pathways

Most of the hospice workers interviewed had never planned to work in hospice. Most had completed training (as nurses, social workers, chaplains, home health aides) for more conventional types of medical care, but key personal and professional experiences pushed them to consider hospice as a work option. Some of these included problems with conventional medicine; struggling with personal loss; experiencing an accident; feeling moved by a divine intervention; or responding to the pressure from someone in their personal network. But once there, almost all workers claimed that hospice work allowed them to learn more about themselves, to become better people, and to fulfill a calling to care. In essence, they found themselves unexpectedly working in hospice, but in doing so, they also “found themselves” through their work. This chapter uses interview data, supplemented by descriptive statistics from my survey of hospice workers, to show the multiple paths by which hospice workers ended up in hospice, and how they thought about their work once there. These data show workers’ commitment to hospice as a philosophy and a type of work, and implicitly discuss the most fulfilling aspects of hospice work. However, this commitment was challenged by the organization of their everyday work lives—something more extensively discussed in Chapter 3.

Chapter 3. Life in Hospice: Expect the Unexpected

Although death and decline is frequently a time of suffering for patients and their family members, it is the context of daily work for hospice workers. The work of hospice is varied, often hectic, and sometimes extraordinary. But, it is also mundane, routinized, and sometimes
even drudgerous. Using ethnographic and interview data, this chapter highlights both the extraordinary and the mundane in the everyday work lives of hospice. It starts by showing how hospice workers structure their days, highlighting that they have a great deal of autonomy and discretion about how to carry out their work, something that work scholars have emphasized increases work satisfaction. However, this discretion comes at a cost when patient care needs increase and workers find that they must “expect the unexpected.” Their work days are often very long, especially as paperwork obligations grow and time spent driving increases. Paperwork and driving are two of the most drudgerous aspects of hospice work. Workers felt that time with patients was generally more rewarding, but even that was subject to increasing routinization as their workloads have expanded over the past few years. Connections to patients, time spent in patients’ homes, spiritual experiences, and personal growth opportunities, on the other hand, were described as extraordinary aspects of the job. As hospices have become increasingly concerned with the bottom line, the tension between workers’ commitment (shown in Chapter 2) and the changing organization of hospice work (shown in Chapter 3) has posed new challenges for hospice workers. Additionally, workers sometimes deal with these challenges in ways that prioritize the needs of patients and their family members over their own self-care needs.

Chapter 4. Death in Hospice: Redefining Dying

Hospice workers’ commitment to caring for those at the end-of-life can be very difficult to sustain (especially as hospice organizations change), as is shown in Chapter 3. However, one way that workers continue to find meaning in the work is through adopting alternative beliefs about the nature of death and dying. The hospice philosophy emphasizes that death is part of life; death is a beginning as much as an ending; and that being present for the dying process is a gift. Hospice workers embrace these alternative conceptions about death, and work to integrate them into their own emotional responses to death and decline. Chapter 4 outlines the various ways that hospice workers redefine death, as well as highlighting challenges that come along with these alternative beliefs. For instance, workers are not always able to respond to patient deaths in ways consistent with their beliefs, especially if they feel intense grief. Some deaths are difficult to think of as a gift, especially when they involve uncontrollable pain, uncontrollable bodies, or abusive family dynamics. Additionally, hospice workers’ alternative beliefs can sometimes lead to stigma from outsiders. Hospice workers often form friendships with their colleagues that permit them to better deal with this stigma and information management. These friendships, along with their alternative belief systems, are the foundation for the hospice subculture. This chapter focuses explicitly on the tension between workers’ desire to make hospice more mainstream, and their realization that this would require tempering their beliefs and assimilating to more conventional ideas about death. Using ethnographic and interview data, this chapter illustrates how hospice alternative beliefs enter into daily work of hospice care providers, but also limits and constraints imposed by these alternative beliefs.

Chapter 5. Emotional Divisions of Labor: Inequality within Hospice

The work of hospice can be emotionally draining. Making connections with patients, witnessing the decline and death of patients, helping family members mourn, dealing with stigma from
others, and supporting co-workers can be exhausting, even for the most hospice-minded staff members. Chapter 5 shows, however, that the burden of the emotionally difficult work is not shared equally by all hospice workers. Some workers provide more emotional support and perform more emotional labor than others, and some workers—regardless of the amount of emotionally difficult work performed—suffer more negative consequences of the work. Using survey and interview data, Chapter 5 parses out how this inequality differentially affects hospice workers’ work satisfaction and intention to leave hospice. It concludes by discussing the kinds of things that workers suggested for making the work less emotionally burdensome for all. This chapter adds to previous discussions of the tensions between commitment and organizational change, as well as providing empirical evidence that the tension between self-care and other care can be detrimental for hospice workers’ own health.

Chapter 6. Constraints on Caring: Structural Challenges to Meaningful Work

Hospice workers in *Caring at the End* generally found their work to be worthwhile, even as the work is hectic, pressured by organizational change, stigma-producing, and unequally distributed. Workers dealt with these challenges within their subcultural group, but some aspects of the work eventually became too difficult to endure. Chapter 6 uses interview and survey data to document aspects of hospice work that made it difficult to sustain commitment. Many of these aspects, specifically increased documentation burden, changing management, and increased emphasis on marketing, are becoming more problematic for workers as Medicare standards change to prioritize efficiency of care over the principles of the hospice philosophy. These structural pressures cause many workers to leave their current job or hospice organization in favor of another organization that they think might be more in line with their ideals, especially related to expectations for time spent with patients. Workers approach these problems from an individualistic perspective, instead of lobbying for changes to the structure of work. This chapter also directly documents the tension between commitment and changes to hospice organizations, while also setting the background for understanding the subculture of hospice workers.

Chapter 7. Conclusion: Emotions, Death, and the Subculture of Hospice Workers

This chapter pulls all of the previous empirical chapters together to show how hospice workers form a subcultural group that provides supports for workers, but also exacerbates existing problems, especially by emphasizing an individualistic stance toward dealing with change. Hospice workers’ experiences reflect tensions between work commitment and organizational change; caring for the self and caring for others; and, assimilation and emphasizing difference. Workers navigate each of these tensions in their daily lives, as is shown in the main chapters of *Caring at the End*. The conclusion moves beyond these findings and larger arguments, however, to discuss future change to hospice and policies that might help retain caring workers (of all kinds). Although many hospice workers are not optimistic about the future of hospice, Chapter 7 grounds their critiques in suggestions for organizational and policy-level changes that will help workers to continue to find meaning in their work. This is especially important right now as the need for care at the end-of-life is expected to increase dramatically, making the problems of end-of-life care workers problems for us all.
Methodological Appendix. Mixed Methods and Managing Emotions

*Caring at the End* is written for a general educated audience, and as such, I will not include all of the methodological details in the introduction. The methodological appendix will further elaborate on the observation process, how my observations informed the interview schedule, how interviews were analyzed, how I used qualitative data to develop the survey questionnaire, how I picked a population from which to sample, and how I analyzed survey data. As this study uses mixed methods throughout, it will be especially useful as a reference for those considering merging qualitative and quantitative methods in their own work. I will also discuss my own emotions and emotional labor experiences throughout the research, adding reflexivity to my study of emotions and work.