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Shifting from Nonprofit to For-Profit Hospice Ownership: The Impact of Privatization on Hospice Employee Working Conditions

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ABSTRACT

This paper seeks to answer how hospice institution type, nonprofit or for-profit, affects nurse and physician working conditions within the industry. I reference a body of empirical literature to characterize the shift in hospice ownership that has occurred in the 21st century from nonprofit to for-profit and, more specifically, the impact that has had on patient and field-specific issues. Defining what exactly is occurring across hospice organizations in the United States and understanding how that effects healthcare workers and patients alike is what motivated the need for this study. Among these organizational differences are inconsistencies in bereavement services, community outreach, disenrollment rates, and patient selection: areas that are not to be taken lightly. Given the gravity of these multi-level differences, I hypothesize that measures of quality for nurse and physician working conditions will negatively correlate with for-profit hospice status.

In order to examine the relationship between working condition quality and hospice institution type, this paper first aggregates literature for a national comparison between nonprofit and for-profit hospice organizations. Literature voices existing concerns with the ever-decreasing proportion of nonprofit hospices in the 21st century. Nonprofit hospices are more likely to provide long term psychological support for patient families, engage with the surrounding community, and enroll patients regardless of condition. There is also concern with hospice staff working conditions, but this area is relatively unexplored. During this time of the COVID-19 global pandemic, it is evident how important our healthcare workers are and the sacrifices they make on our behalf. This paper performs a quantitative overview alongside a qualitative study to address the question of whether privatization has impacted hospice employees.

To understand the significance of hospice privatization, I analyze data from the National Hospice and Palliative Care Organization. The data includes annual reports that contain statistics regarding hospice organization tax statuses and the ratios of nonprofit to for-profit hospices over the years. This data provides a glimpse into the significance of the shift from nonprofit to for-profit hospice and describes a trend that shows no signs of stopping. However, numbers only tell one side of the story and a qualitative study with individuals involved in hospice care offers a relatable perspective. I conduct interviews with participants at the University of Chicago Medical Center, Joliet Area Community Hospice, and Hospice of Kankakee Valley. In the light of my study, I summarize my findings and suggest policy solutions that have the potential to mitigate the challenges that hospice employees face.

Contrary to the hypothesis, my study is unable to observe any significant differences between employee working conditions in nonprofit versus for-profit institutions. However, there is evidence to suggest that known issues to the hospice specialty are negatively affecting the work force. This suggests that focusing on these widespread issues within hospice care is the next step in improving how hospice care employees are looked after. Future studies on the topic should focus on a more in-depth analysis of how past policies are working towards addressing these larger issues within hospice.

INTRODUCTION

Hospitals are considered the face of medical care and are responsible for the treatment, both medical and surgical, of the sick and injured regardless of age. Hospice, a less discussed sector, is an equally important yet highly sensitive part of medical care in the United States. Dying is an inevitable part of life yet clinical observation points to the issue that hospitals are ill equipped to deal with the emotional needs of a dying patient.[i] Typical hospital protocol focuses on the present; by nature of the industry, general physicians are better equipped to treat patients who can be cured rather than ones hospitalized with terminal illness. In healthcare, ethical considerations govern all decision-making in a field where peoples' lives are at stake. For example, a plethora of research has been conducted on patient prioritization in circumstances of limited resources during emergency medical care.[ii] To no one's surprise, decision-making is heavily influenced by ethical principles such as vulnerability, social utility, and fairness.[iii] Therefore, as the end-of-life approaches, hospitals take a backseat to focus on cases that have a clear solution.

Hospices take the opposite stance: as the likelihood of the end-of-life increases so does the responsibility of hospice care. Rather than customary hospital protocols, intense hospice care focuses on aggressive symptom management and patient psychosocial support.[iv] However, successful end-of-life care is relative and a sensitive issue especially for patients and their families. The complexity of end-of-life care decisions is undeniable due to the high levels of emotion, grief, and fear of loss that are associated with it. Emotions can often cloud family's judgement when evaluating the care given to their loved ones, and the true quality of delivered care is hard to discern. Literature on patient families' perceptions of hospice vary but suggest

that families of patients enrolled in hospice are unhappy with the program.[v] While it is important to understand the implications this may have, I introduce high emotional levels as a confounding variable.

To expand on the complexity and sensitivity of hospice, I can speak to the impact emotions can have on perceptions of hospice care.

> I sat by her bedside, holding her hand between mine as she stared up at the beige colored ceiling. It was my time to say goodbye. I leaned forward, "Hi grandma, it's your grandson Timothy." We sat there for 10 minutes, her in the hospice bed, and me on a wooden stool. I gave her one last hug and one last, "I love you," and let go. A few hours later my grandmother passed away from Creutzfeldt-Jakob disease, a fatal neurodegenerative condition, with her family by her side.

In June 2018, my grandmother collapsed. Initially, it was believed that she may have suffered a stroke but after testing, the doctors confirmed that it was not and released her from the hospital. Later that week, her condition deteriorated further and, this time, the doctors suggested that she may have Creutzfeldt-Jakob disease, an incurable condition that results in death within a year. While her diagnosis was still up in the air, doctors were with her around the clock, trying different medications and curative treatments. Yet, despite their best efforts her condition worsened rapidly, and, within a week, the medical team spoke to us about hospice care. In early July, she was discharged from the hospital to be cared for by a hospice in the Bronx where the focus would be to help her perform everyday necessities and alleviate the symptoms of her disease; she passed away on July 24th.

My family's view of hospice is very negative, and I can attest to the strained nature of the work that hospices are tasked with. Hospice was a scapegoat for all the negativity, raw emotion,

and sadness surrounding my grandmother's condition. I felt those emotions and am guilty of them as well. But after the fact, I recognize that those negative feelings towards hospice did not stem from issues with quality care but from the sensitive nature of end-of-life services.

Speculation, positive and negative, surrounding hospice medicine ties back to quality patient care. How is appropriate care defined? The National Health Service defines it, "Appropriate care means the selection, from the available interventions that have been shown to be efficacious for a disorder, of the intervention that is most likely to produce the outcomes desired by the individual patient."[vi] The definition expands to discuss intervention guidelines, most of which focus on patient involvement: availability, consent, and transparency. First, any medical intervention must be well-documented and accessible so that it can be performed to a sufficiently high standard. Second, patients need to be given adequate information about all available interventions. Finally, it follows that patients must be fully involved in discussions about the likelihood of different outcomes with and without intervention, and about any complications that they might encounter. Appropriate care puts the well-being of the patient first and foremost, as it should, and advocates for the negligence of external factors such as profit margins.[vii]

Hospice can be broken down into four categories, with for-profit, 65.2%, and nonprofit, 23.1%, being the two largest constituents as of 2018. As of 2014, 47.6% of hospice providers identified as for-profit while 27% identified as nonprofit. Over the past decade, there has been significant growth in the hospice industry but only in the for-profit sector whereas nonprofit and government hospice providers saw minor to sharp declines. In theory, the for-profit and nonprofit labels of a hospice should not make a difference in the quality of care received. The regulations that govern these institutions are the same: State law and the Code of Federal

Regulations set strict guidelines for hospice care providers.[viii] In addition, hospice services need to provide multiple levels of care, all of which require specialized, trained staff. Its popularity has grown significantly as medical service professionals continuously encourage all individuals who have received a terminal diagnosis to enroll. From 2012 to 2017 there has been a steady increase in Medicare beneficiaries, which make up the majority of patients, who received hospice care: 1.27 million in 2012 to 1.49 million in 2017. As the demand for end-of-life care increases, so does the number of hospices around the US. In 2017, there were 4,515 hospice service providers, which is a 22% jump from the 3,700 providers in 2013 over the course of four years.[ix] However, these large increases are not without reason.

With time, hospice care and the organizations responsible for it become increasingly important. America is getting older: an aging population and shifting demographics does not bode well for the country's overall health. Seniors, defined as ages 65 and above, already account for the largest portion of healthcare. According to US Census Bureau projections, 1 out of every 5 U.S. citizens will be 65 or older by 2030 which means that within a decade, older people are projected to outnumber children for the first time in history. With an increased elderly population comes an increased number of individuals afflicted by chronic and non-communicable diseases such as Alzheimer's, cancer, and dementia.[x] This shift will undoubtedly increase the number and needs of patients seeking end-of-life care placing enormous strain on the healthcare system. As a result, current issues with hospice, not limited to employee well-being and high-quality patient care, will only be amplified and increasingly scrutinized. Thus, the need to pay increasing attention to the state of hospice care sooner rather than later.[xi]

Literature has pointed to the ever-growing demand for hospice and palliative medicine physicians in perspective with the limited supply. As of 2018, the US supply of hospice and

palliative medicine specialists is 13.35 per 100,000 adults 65 or older. Using regression analysis Lupu et al. projected that "current training capacity is insufficient to keep up with population growth and demand for services."[xii] The general issue of limited supply in hospice care is a well-documented area of study, but this paper specifically aims to inform policy and academia about the distinction between for-profit and nonprofit hospice services. More specifically, this study provides an analysis of whether institution type in the hospice industry significantly affects staff working conditions. First, a quantitative overview will define the extent of hospice privatization and will characterize a trend that looks to continue. Then, an analysis will be performed on a qualitative data set collected from nurses, physicians, and patients across a variety of hospices in the greater Chicago area. In person and remote interviews will be conducted to learn more about personal experiences and working conditions at nonprofit and for-profit affiliated hospice organizations. From the collected data, the study will explore correlations with staff opinions and perceptions of their respective hospice employers. If the hypothesis is correct and measures of quality for nurse and physician working conditions negatively correlate with for-profit hospice status, the privatization of hospice institutions must be addressed immediately. On the other hand, no effect will indicate that the current trend may not be detrimental to the hospice industry with regards to employee welfare. To contextualize the findings, this paper will analyze recent health policies and reform to see what policymakers are doing to address the increasing number of for-profit hospices and other hospice related issues.

BACKGROUND

Standardization

As mentioned in the introduction, hospice care is governed under tight regulations for the service of quality patient care. The National Hospice and Palliative Care Organization outlines four levels of care that are meant to encompass and cater to hospice patients that require differing intensities of care during the course of their disease:[xiii]

1) Routine Hospice Care is the most common type of hospice care. In this case, the patient has elected to receive hospice care in the comfort of his or her own home. Hospice staff are obligated to provide the necessary services to reduce pain and maximize comfort.
2) Continuous Home Care is provided to patients with more severe and acute medical symptoms. Care is provided for between 8 and 24 hours a day by qualified nurses, in addition to hospice aides, to mitigate pain or symptom crisis.
3) Inpatient Respite Care serves as a relief system for the patient's primary caregiver, typically a family member. It can be provided in a designated hospice facility or other certified facility that has a 24-hour nursing staff. At this point, the patient is no longer at his or her residence.
4) General Inpatient Care is provided in cases where pain and acute symptoms need to be treated in a designated hospice facility such as a Medicare certified hospital, hospice inpatient facility, or nursing facility. Once again, a 24-hour nursing staff is needed to provide direct patient care and the patient's residence is no longer in the picture.

The framework and governing policies are in place to ensure standardized care across for-profit and nonprofit hospice organizations. Implementation and enforcement of these measures are the keys to a regulated hospice industry.

The Great Hospice Debate

Hospice care is a complex issue that has recently come under scrutiny due to the recent explosive growth in the number of for-profit hospices. The sector's rapid growth has sparked the ongoing debate about how to best provide end-of-life care in terms of both quality of life and cost effectiveness. Proponents of the mission-focused hospices represent one side of the debate. They argue that a hospice organization's tax status can influence the provision of services and skew priorities in the balancing act between shareholders and patients. For-profit organizations defend themselves, claiming that their organizational model allows better access to capital to enhance and ensure high levels of quality care. Both sides present valid arguments and the debate raises questions meant to hold the hospice industry accountable. Has the mission and philosophy of hospice changed? Has nonprofit or for-profit status affected the quality of hospice care? Are there economic incentives driving decision-making? Do patients enrolled in hospice receive proper care and attention? Literature has sought to answer many of these questions and a review of their results may provide some answers.[xiv]

Culture, Tax Status, and Provision of Services

Although fundamentally similar, nonprofit, and for-profit hospice organizations have significant cultural and operational differences. While all hospices serve patients and employ physicians and nurses, for-profit hospices generate a return for investors. As Yivette Doran, chief operating officer at Saint Thomas Medical Partners said, "The culture at for-profits is business-driven. The culture at nonprofits is service-driven."[xv] Additionally, nonprofit hospices are not

required to pay taxes to the state or federal governments on reimbursements they receive from Medicare claims. Tax exemption is standard for all registered nonprofit organizations and has a major financial impact on hospices and the communities they serve. Paying taxes influences corporate culture and requires cost consciousness and operational discipline. Due to the added costs, for-profit hospices generally must be more cost-efficient and aware of the financial pressures associated with their organizational status. However, the added pressures come with benefits in the form of scale. For-profit hospices, relative to their nonprofit counterparts, have more access to capital in the form of investors. This allows them to grow and make decisions rapidly due to a readily available stream of capital: a luxury that many nonprofits do not have.[xvi]

Although nonprofits bypass sales taxes, property taxes, and others, they still have expenses to cover. Fundraising is an important part of that and allows nonprofit hospices to not only raise money but also engage with the community and promote their goals. Nonprofit hospices have permission to host fundraisers and solicit donations from the community with the goal of using those funds for patient-driven goals. On the other hand, for-profit hospices are prohibited from performing community fundraising, but to circumvent this issue, they often establish separate nonprofit foundations to have that option. Nevertheless, regardless of business structure, all hospice providers work under the same mandate: to provide the highest quality end-of-life care to patients and families. In theory, this indicates that care is standardized across the organizational field, and the identified shift is relatively harmless and simply a product of market pressures.[xvii]

LITERATURE REVIEW

The ever-growing organizational field of hospice care is heavily scrutinized due to the sensitive and emotional nature of its mandate. I begin this section by characterizing the nonprofit to for-profit shift in hospice ownership that has occurred mostly in the 21st century. Then, I identify prevalent issues that are related to for-profit ownership labels: bereavement services, community outreach, disenrollment rates, and types of patients enrolled. In other words, a multi-level comparison between nonprofit and for-profit hospice organizations. My goal is to address working conditions of hospice employees and identify other issues that compromise workers' ability to perform at the expected level. I also aim to contribute novel insights to the already existing literature and to provide policy recommendations for the state of Chicago that may be applicable on a larger scale for the United States. To do so, I present existing literature concerning hospice employees, analyze it, and identify what my research can contribute. Having discussed the theoretical differences between nonprofit and for-profit institutions, I expect there to be differences in scale: for-profit hospices should be larger organizations whereas nonprofit hospices should be smaller unless they are associated with a larger entity such as a university. Given the scale, I hypothesize that for-profit hospices will be more focused on the business side rather than paying attention to the conditions of their employees.

Section 1: Shift in Hospice Ownership from Nonprofit to For-profit

Many scholars explore the relationships between nonprofit and for-profit hospices. Research has pointed to significant shifts in hospice ownership and characterized the trend through numerical analysis. From 1999 to 2009, the most prominent trend in the hospice industry was the shift in ownership type from nonprofit to for-profit ownership. More than 40% of Medicare-certified hospices experienced one or more changes in ownership, and four out of

every five new entrants were for-profit. These numbers are staggering. In 1999, 62% of the 2,225 hospices in the United States identified as nonprofit. By 2009, that number declined to 35% after the entrance of 1,710 new hospice organizations, 80% of which were nonprofit. Contrastingly, the share of for-profit hospices nearly doubled, jumping from 27.4% to 52.1%. The percentage jumps characterize the shift occurring from 1999 to 2009 but do not address the number of organizations that changed ownership: a nonprofit becoming a for-profit institution or vice versa. By 2009, about 3,350 hospices were in service. 44% of the hospices that continuously operated over the decade changed ownership type at least once, indicative of an unstable environment. Of that 44%, the majority of hospice organization transitioned from nonprofit to for-profit status characterizing the substantial turbulence in the hospice industry.[xviii]

Using recent statistics from the *Vital and Health Statistics Reports*, about 3,700 registered and certified hospice services were active from 2012 to 2013. 56.6% identified as for-profit and 29.7% as nonprofit. The proportion of for-profit organizations jumped 4.5 percentage points while the proportion of nonprofit organizations dropped 5.3 percentage points. From 2013 to 2014 about 4,000 hospices were in service demonstrating small but steady industry growth and new entrants. 60.2% identified as for-profit and 25.9% as nonprofit. The proportion of for-profit organizations jumped 3.6 percentage points while the proportion of nonprofit organizations dropped 3.8 percentage points. From 2015 to 2016, 4,300 hospices worked to provide high quality end-of-life care. 63% identified as for-profit and 22.8% as nonprofit. Once again, the proportion of for-profit organizations jumped 2.8 percentage points while the proportion of nonprofit organizations dropped 3.1 percentage points. It is clear there is a consistent increase in the ratio of for-profit to nonprofit hospice organizations, indicative of the trend.[xixxxxxi]

Section 2: Issues Correlated with For-Profit Status

Whether a hospice identifies as for-profit or nonprofit, the quality of care should not change based on ownership status. In scholarship, there was uncertainty as to whether hospice ownership impacted cost and quality of hospice care as well as patients' access to it. As a result, it was evaluated as a critical area for future research.

(a) Bereavement Services

Hospice care extends beyond the patient to the family. Medicare certification requires bereavement services be provided. The mandate reflects the principle that the patients and families are critical components of high-quality palliative care. However, these services are not tied to Medicare compensation, providing limited financial incentive for hospices to comply with more than the bare minimum.[xxii] Before continuing, bereavement must be defined: it is the time of mourning after the loss of a loved one. Medicare "defines bereavement counseling as emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment."[xxiii] It is the responsibility of the hospice care team to help surviving loved ones through the process of grieving for about a year after a patient's death. How does ownership affect the scope of care provided to family members? This question is answered on four levels: 1) provision of bereavement services to the family; 2) provision of bereavement services to the community; 3) provision of labor-intensive family services; 4) provision of comprehensive family services.[xxiv]

First, bereavement services to the family is defined as providing at least 80% of the required services. Second, bereavement services to the community refers to providing it to patient families outside of network. Third, labor-intensive means going beyond what is required such as providing screening for both depression and grief. Finally, comprehensive service

indicates the provision of an extensive array of services targeted at family members. As an industry, 78% of hospices provided bereavement services to the family and 76% provided them to the community. Yet a troubling finding was that nonprofit hospices were more likely than for-profit to provide bereavement services to the community. More specifically, for-profit hospices had an odds ratio of 0.53. On the other hand, nonprofit hospices maintained an odds ratio of 1.00. For the purpose of this literature review an odds ratio greater than one means an increased occurrence of the event whereas a ratio less than one indicates a decreased occurrence.[xxv] Yet, there was no observed difference between nonprofit and for-profit hospices when it came to levels one, three and four. An explanation for the odds ratio difference in level two can be explained by the following: nonprofits are more reliant on the community when it comes to fundraising and support, which creates an incentive to provide services to the community. Such incentives are diminished on the for-profit side. This is one potential explanation of the identified difference in ownership.[xxvi]

(b) Community Outreach

In the community, hospice is a driving force for social change and sets the standard for end-of-life care for terminally ill patients and their families. Through activities such as community outreach, research, clinical training, and charity care, hospices have made and can still improve the care of people who are dying and reduce barriers to end-of-life-care.[xxvii] A study by Aldridge et al. evaluated a given hospice's presence in community outreach via the following criteria: 1) service as a training site; 2) published relevant research; 3) participation in charity care. Both training and research have long-term implications and the potential to spur improvement in the hospice industry. Hospice care requires a complex skill set that involves ongoing training and updated practices. The hospice industry already faces a massive deficit of

12,000 palliative medicine physicians which is only exacerbated every year.[xxviii] Training builds a workforce that understands best practices and the keys to success in a hospice environment while also providing an avenue for entrants to join the hospice pipeline. The largest discrepancy is observed when it comes to serving as training sites: 55% of for-profits comply versus 82% of nonprofits. In addition, 18% of for-profit hospices conducted relevant research for publication whereas 23% of nonprofit hospices did. There was very minimal difference in participation in charity care. These statistics are worrying given the dwindling nonprofit hospice sector. If trends continue, the hospice sector may see negative outcomes due to lack of proper training and a lack of driving research to continuously make hospice more effective.[xxix]

(c) Disenrollment Rates and Patient Selection

Hospice disenrollment involves the discharge of a patient for a variety of reasons and motivations. Specifically, for hospice, disenrollment can be initiated either by the patient or the hospice. From the patient side, he or she may want to pursue a novel, curative treatment, be dissatisfied with hospice care, or other logistical reasons. A hospice may officially discharge a patient if he or she no longer meets eligibility criteria but there may be underlying motivations. For-profit hospices were found to have an average disenrollment rate of 10% while their nonprofit counterparts averaged 6%. Given the other issues that seem to be tied to ownership status, the few percentage point difference is a cause for concern. Hospice organizations should not discharge patients that require more expensive care to survive and rather they should stand strictly by their mandate to provide the highest quality end-of-life-care.[xxx]

The types of patients enrolled can be indicative of hospice priorities. Theoretically, the breakdown of patient conditions and discharges should be uniform and standardized despite ownership. For example, patients with cancer and patients with dementia should receive the

same high level of care. However, this does not seem to be the case. First, for-profit hospices were 17% more likely to discharge a patient with noncancer diagnoses than nonprofit hospices. This indicates that for-profit organizations prefer to treat noncancer patients due to the expensive medication and treatments required during their stay. Second, for-profit hospices were 15% more likely to have long term care referrals. Long term referrals are patients that require long term care, low maintenance medical care such as dementia patients. Finally, for-profit hospices were 8% more likely to accept patients that were government payers. Government payers are patients covered by primary reimbursement sources like Medicare, Medicaid, and other government reimbursement programs. For-profit tendencies to prioritize patients with longer and less difficult prognoses presents a complex problem.[xxxi]

Section 3: Hospice Employees and Thesis Contributions

Staffing patterns within the hospice industry are a key component of high-quality hospice care. Many scholars wanted to explore interdisciplinary staffing patterns across nonprofit and for-profit hospice. Findings showed that for-profit hospices had significantly fewer registered nurse full time employees as a proportion of the nursing staff, fewer medical social worker full time employees as a proportion of psychosocial staff, and fewer clinician full time employees as a proportion of total staff.[xxxii] These observations suggest that ownership type leads to significant differences in hospice staffing patterns.

Additionally, there is an abundance of existing literature concerning hospice employees using qualitative methods to learn more about nursing and caregiver experiences within the hospice industry. However, none of them address these experiences in the context of the nonprofit to for-profit transition. For example, a top study interviews nurses on their experiences with delirium in a hospice setting while another interviews hospital nurses about how much they

know about the field of hospice care.[xxxiii,xxxiv] While some publications address staff perspectives, they do not focus on the perspective of employees who work in a for-profit hospice environment versus a nonprofit one. The main thesis of this BA is to address whether staff working conditions and opinions vary significantly based on ownership labels. The following main topics will add to the existing literature on hospice employees: personal work experience, hours worked, perspective on hospice organizations, and the number of patients responsible for. Expanding knowledge on these topics will improve understanding of how the shift from nonprofit to for-profit hospice has affected hospice employees.

METHODOLOGY

Within this section, I will explain my methods of data collection which include a quantitative analysis of national data sets, and a multiple hospice case study using interviews with hospice care employees. While the case study is the focal point of my research, the national data sets provided by the National Hospice and Palliative Care Organization (NHPCO) and the U.S. Department of Health and Human Services offer a relevant statistical collection of hospice data.

National Data Sets

The NHPCO is the leading organization representing hospice and palliative care providers whose mission is to lead and mobilize social change for improved care at the end of life.[xxxv] Although it is a more generalized organization aimed at overall healthcare, the U.S. Department of Health and Human Services also addresses long-term care providers and services users in the US which involves hospice.[xxxvi] They provide annual “Vital and Health Statistics” detailing an analytical and epidemiological study of data from their own conducted national

study of long-term care providers which include adult day services centers, home health agencies, hospices, nursing homes, and residential care communities. The report includes a broad arrangement of detailed statistics about hospice organizations in the United States. This paper will address the following: staffing, financial information, services provided, and affiliation, nonprofit or for-profit.[xxxvii] Providing an in depth quantitative summary of these statistics will provide context into existing patterns that distinguish nonprofit from for-profit hospice organizations, if any. The revenue and expense breakdowns are areas of elevated interest for future research. Trends in these areas could help explain why hospices are transitioning away from nonprofit ownership.

Case Study

In order to understand the impact of the nonprofit to for-profit shift on employee working conditions, the sample population must be defined. The following are the hospices and medical centers referenced by participants in the qualitative study:[xxxviii]

For-Profit

1) Vitas Healthcare
2) Chicago Hope Hospice

Nonprofit

1) Hospice of Kankakee Valley
2) Joliet Area Community Hospice
3) University of Chicago Medical Center
4) JourneyCare Hospice

A case study is a research methodology that is an intensive study about an organization which is aimed to allow generalization over several, similar units. It involves the intensive, systematic investigation of data that can relate to several variables.[xxxix] In the scope of this paper, a case study will help examine the complex phenomena of the hospice shift from nonprofit to for-profit in a natural setting to increase overall understanding. A case study approach narrows down the broad, complex topic of organizational status into manageable research questions: for example, "What are working conditions like at this organization?" It also allows for the collection of both qualitative and quantitative data sets, a mixed approach. Ideally, the response rate from the hospices will be 100% and a multiple-case study can be performed based on the evaluation of several, comparable cases which will provide a better answer to the research question. While a select few hospice organizations will be used in my case study, I extend the "map" of the field to include other hospices that make up the organizational field. The inclusion of multiple hospice organizations will help bring into consideration each's complex and unique features that may not be shared among the others in the sample.

Interviews

The case study conducts qualitative interviews with hospice employees at organizations named in the already outlined multiple-case study. The goal is to better understand the experiences of employees in differing hospice settings through structured interviews with nurses, physicians, and hospice patient families. Nurse and physician specific questions are designed to learn more about their experiences and daily routines. Key information includes how their experiences at their respective hospices differ when it comes to nonprofit or for-profit affiliation, if at all. To supplement the employee interviews, members of patient families will be asked questions about their expectations for hospice care workers. Their responses will give

perspective on the added pressures of living up to the expectations of patient's loved ones. These are the questions that will be asked to the nurse and physician participants:

Nurse Interview Questions

1) When did you start working at this hospice organization?
2) How many patients are you responsible for daily?
    a. Has that number adjusted at all?
    b. Do you think it is too many or too little?
3) Are you able to provide enough attention to each patient?
4) How many hours do you work a week? Hours a day? Include charting and other administrative activities.
    a. Do you work on weekends?
5) How would you rate your experience with the job on a scale of 1 to 10 with 1 being terrible and 10 being amazing?
6) How would you rate your work/life balance on a scale of 1 to 10 with 1 being terrible and 10 being amazing?
7) Hospice care is a very difficult field for the caregivers as well as the patients. How do you manage the difficulty of the position?
8) Have you worked at other hospice organizations?
    a. If so, was your experience at the other hospice organization any different?
    b. In what ways?
9) Are you aware of the existence of both nonprofit and for-profit hospices?
    a. What are your perceptions of each of these?
10) How would you characterize the focus of the company?

a. Is there anything you can do or say to change the focus of the company or is there little room for feedback?

b. Does the company ask for feedback from its nurses?

11) Would you do anything to improve your job right now?

12) Would you like to add any additional comments about your role as a hospice nurse?

Physician Interview Questions

1) How long have you worked in the hospice field?

2) Are you aware of the existence of both nonprofit and for-profit hospices?

    a. What are your perceptions of each of these?

3) How familiar are you with the large-scale transition from nonprofit to for-profit hospice organizations?

    a. If YES, can you please elaborate on the facts surrounding this situation?

        i. What is your opinion on the shift?

        ii. How do you think the shift affects hospice employees with regards to lifestyle and work life?

        iii. How do you think the shift affects hospice employees with regards to patient care?

        iv. What should be done to address the shift and any related issues stemming from it?

    b. If NO, move on to the next question.

4) How many patients are you responsible for daily?

    a. Has that number adjusted at all? Are more experienced physicians responsible for more patients?

    b. Do you think it is too many or too little?
    c. Are you able to provide enough attention to each patient?
5) How many hours do you work a week? Hours a day? Include charting and other administrative activities.
    a. Do you work on weekends?
6) How would you rate your experience with the job on a scale of 1 to 10 with 1 being terrible and 10 being amazing?
7) How would you rate your work/life balance on a scale of 1 to 10 with 1 being terrible and 10 being amazing?
8) Have you worked at other hospice organizations?
    a. If so, which one?
    b. Were they nonprofit or for-profit?
    c. Was your experience at the other hospice organization any different from UChicago Medicine?
        i. If so, in what ways?
9) How would you characterize the focus of the palliative care/hospice department at University of Chicago Medicine (UCM)?
    a. Is there anything you can do or say to change the focus of the company or is there little room for feedback?
    b. Does the company ask for feedback from its physicians?
10) Would you like to add any additional comments?

To reiterate, the most significant portion of data collection involves interviewing employees at both nonprofit and a for-profit hospices to provide a basis for case study comparison: keeping in mind the aim of the research project, which is to document the personal experiences of hospice employees and shed light on working conditions, employee perceptions, and opinions.

Limitations

Like any study, this project's methodology has limitations. Given its case study nature, my overall results are limited by the scope of the nonprofit and for-profit hospices selected for the interview process. My research is primarily based Chicago and may not be generalizable to the wider hospice organizational field. In his book, "Street-Level Bureaucracy," Michael Lipsky introduces the term "street-level bureaucrat" as a descriptor for front-line officials that interact directly with the public: in terms of relevance for this research paper, nurses and social workers neatly fit the definition. The issue is that each individual is unique and routinely exercises discretion that is beyond systematic control. In other words, hospice's street-level bureaucrats have specific practices, policies, and ideologies that may not be directly applicable to other hospice systems in the field. Because of this specificity, Lipsky argues that there are limited ways of challenging this discretion and overseeing these practices. For this reason, my policy recommendations, trends, and collected data are primarily geared towards hospice organizations in Chicago.[xl]

In addition, my literature review discusses issues that stem from the nonprofit to for-profit shift. Given the range of differences already observed within hospices of differing ownership types, seeing things from an employee perspective may be insightful within the context of work environment. The continuously growing body of work pointing to fundamental

differences between for-profit and nonprofit hospices may be symptomatic of larger issues within hospice care. The inevitability of greater demand for end-of-life care, that comes with an aging population, should motivate efforts to identify issues within the hospice industry as soon as possible.[xli] This also prompts the search for solutions and investigation into the feasibility of later policy recommendations.

DISCUSSION

While extensive research has been done on the impact of hospice privatization on patient care, there is a lack of qualitative and quantitative research regarding the well-being of nurses and physicians in the hospice care industry. This study seeks to make up for this gap by reviewing the personal experiences of hospice care workers from the Hospice of Kankakee Valley, University of Chicago Medical Center, and Joliet Area Community Hospice. I hope to give a voice to hospice employees that would not necessarily have the chance to express their opinions and share their stories about their time in the hospice industry. Throughout this section, quantitative analysis of numerical ratings will put a number to the quality of the work environment at different hospice organizations. In addition, anecdotes from the qualitative interviews conducted with caregivers, patients, and their families will be used to discuss and analyze the landscape of the hospice industry. However, to protect the identities of the participants involved, aliases will be used to reference quotes and other interview data discussed in this section.

Participant #1 is relatively new to hospice care. She has been a nurse for over 10 years but has only recently become a member of the hospice care community. However, even in her limited experience, she is no stranger to the unpredictability of hospice. In her own words, “It’s

kind of how it goes." Other participants have echoed her sentiments. As an outsider, it is easy to assume that medical care is unpredictable, and hospice is no exception. Nevertheless, it is important to understand the perspectives of those treating hospice patients daily.

To begin, I discuss barriers to successful hospice care, specialty-wide issues, and patient expectations from caretakers. Then, I address participants' responses to questions about patient workload, hospice experience, and scaled ratings for work-life balance. Next, I compare the disparities between nonprofit and for-profit organizations. Included in these sections are brief quantitative overviews of publicly available data from the National Hospice and Palliative Care Organization (NHPCO). Finally, I consider participants' thoughts on the hospice industry overall to highlight critical areas to be addressed via policy recommendations.

Involved Hospice Organizations

Nurses in the sample were affiliated with both for-profit and nonprofit hospices in the Chicago area. The nonprofit organizations are the University of Chicago Medical Center, Joliet Community Hospice Care, JourneyCare Hospice, and the Hospice of Kankakee Valley in Chicago, Illinois. The for-profit organizations are VITAS Healthcare and Chicago Hope Hospice also in Chicago, Illinois.

The University of Chicago Medical Center (UCM) is a nonprofit, academic medical center located in Hyde Park on the South Side of Chicago. The physicians interviewed for this project practice at the palliative department of UCM and often refer patients to a number of hospices in the Chicago area, including VITAS Healthcare.

The Hospice of Kankakee Valley is a community centered support hospice that is nonprofit affiliated. It was founded as a volunteer hospice in 1982 and has grown into a larger, but still small hospice organization.

JourneyCare Hospice is a nonprofit hospice organization that came about as a result of a merger of Chicago-based Horizon Hospice, Barrington-based JourneyCare, and Midwest Palliative and Hospice CareCenter: three nonprofit, community-centered hospices.

VITAS Healthcare is the nation's leading provider of hospice care and is a company that operates programs in fourteen states. It is affiliated with for-profit services and is a subsidiary of Chemed Corporation, a publicly traded company. It was founded in 1978 as a nonprofit hospice but in 2004, it was acquired by Chemed and shifted to for-profit status.

Chicago Hope Hospice is a relatively new for-profit hospice institution that became accredited in 2016. Since then, it has provided hospice care services to sick patients in the Chicago area.

Societal Expectations for Hospice Employees

Families and patients expect hospice employees to maintain high levels of quality care for their loved ones. When that quality of care is not considered adequate, hospice employees often feel the frustration of families and patients. The medical care system, the hospice organization, and patient-related individuals, all expect hospice workers to be able to work tirelessly to ensure proper care of the patient. While patient care is a huge part of hospice, it is crucial to consider the potentially detrimental effects on the well-being of the hospice workforce. For example, one of the participants I spoke with was very aware of the "sensitive" nature and "high expectations" of working at a hospice institution. Her experience working at multiple

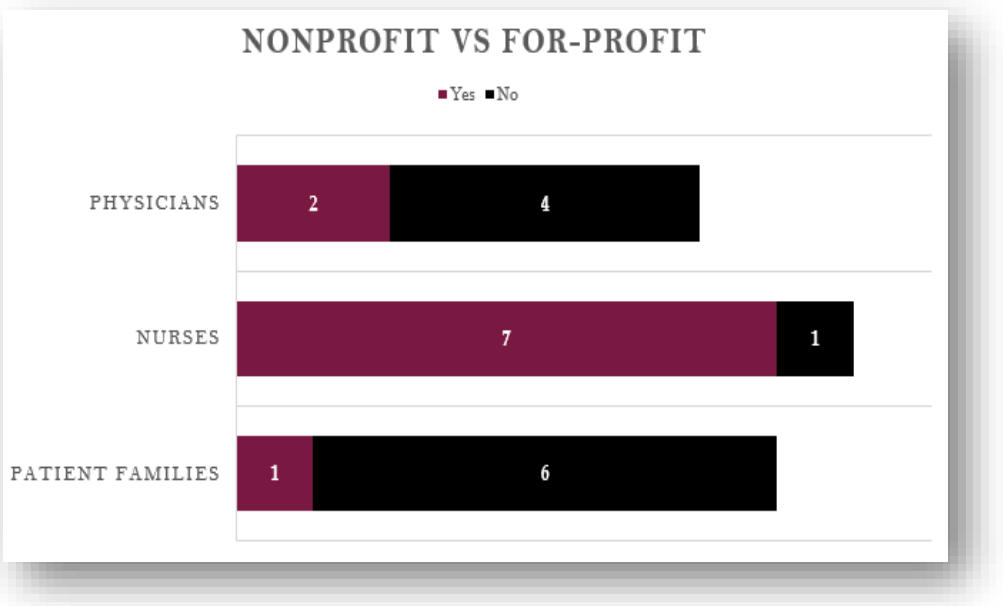
hospice organizations is telling of the consistent expectations throughout the industry. Participant #21 told me, “I just want what’s best for my father.” This mindset was echoed by all seven participants who had either a relative or a friend in hospice care. Societal expectations set the bar for what is expected from the hospice workforce, and this discussion seeks to understand what nurses and physicians give up in order to meet those expectations.

Hospice employees are regulated officially by the NHPCO, but societal expectations set the standard for nurse and physician interactions at the workplace. The official guidelines are organized into nine main categories: patient and family/caregiver-centered care, ethical behavior and consumer rights, clinical excellence and safety, inclusion and access, organizational excellence, workforce excellence, compliance with laws and regulations, stewardship and accountability and performance measurement. Looking closer at patient and family/caregiver-centered care reveals a strict set of principles that hospice employees abide by. For example, “the patient, family, caregiver, and other individuals identified by the patient are the unit of care.” These guidelines, while truthful and correct, are associated with a different type of pressure than the societal pressures that face hospice employees daily. Rather than a set of rules and principles to abide by, societal expectations are a collection of blurred and implied necessities for any physician or nurse. Study participants were asked whether patient families added stress to their already busy lives. For the overwhelming majority, patients’ relatives made their expectations very clear and they often “felt the heat” as one interviewee put it. It is important to understand that physicians and nurses are aware of the stakes involved in hospice care and how much families care about their loved ones. Hospice working conditions are not defined solely by how employees are treated by organizations, but also how they are treated by those that they are

responsible for. Interviews with patient families provide perspective on the non-employer aspect of stress that is placed on the shoulders of hospice care employees.[xlii]

Knowledge of Nonprofit to For-Profit Shift

For the most part, participants expressed little to no knowledge of the country-wide shift from nonprofit to for-profit hospices. The interviewees can be separated into three broad categories: physicians, nurses, and patient families. Of the seven interviews conducted with patient families, six were unaware of the country-wide shift from nonprofit to for-profit hospices in the 21st century. Similarly, four out of the six physicians interviewed were also unaware of the shift taking place. The nurses seemed to be more informed about hospice affiliations, and six out of the eight were aware of the increasing presence of for-profit hospices in the United States.



It is not surprising that patient families are overwhelmingly unaware of the affiliation shift in the hospice industry. To be aware of it, one needs to read literature concerning the shift or be well-versed in national hospice data published on a yearly basis. Participant #2 is the son of a current hospice patient. He knew that nonprofit and for-profit labels existed for hospice organizations. When choosing a hospice care organization for his father, he encountered many differently affiliated organizations. However, when the privatization of the hospice industry was brought up, he had no idea that this was the case. He told me that he was "not surprised" given the importance of money in modern day America. Other family members of hospice patients indicated that they were "unaware" of such a significant occurrence. I spoke with participant #3 who said that he was not even sure how to even come across "this kind of information": a sentiment that was echoed by other participants.

On the other hand, physician's lack of knowledge was unexpected given their proximity to hospice care. From the responses, knowledge of the shift seemed largely dependent on the position of the physician within the department. Those involved in both the patient and

administrative aspects of hospice care understood the distinction between for-profit and nonprofit and were familiar with literature concerning the shift. Whereas the physicians involved mainly on the patient side were less aware of these topics. Participant #4 is a palliative care physician at the University of Chicago Medical Center (UCM). Over the years her role in the department grew more administrative, and she was "aware" of the shift as well as the distinctions between for-profit and nonprofit affiliations. She told me that the line between them is becomingly increasingly blurred: "My general feeling is that even not for profit hospices are moving more in the direction of either budget neutral or profitable hospices largely because the operating budgets are very, very constrained. I feel that the business model is changing in hospice care." On other end of the spectrum were the rest of the participants. I spoke with participant #5, also a palliative care physician at UCM. She told me that she is "assigned to work with many patients on hospice" but is only "vaguely" familiar with nonprofit and for-profit labels in the hospice setting. When pressed further, she was unable to speak "in detail" on the topic which was echoed by participants #6, #7, #8, and #10 all of whom are physicians at UCM. One said, "That's actually really interesting. I didn't realize how big of a shift there was from nonprofit to for-profit although I shouldn't be too surprised. I think there is a similar shift in the medical care industry as well. People trying to make a dollar." Another said, "Honestly, I don't really know anything about that…I just don't know anything about the business shift like at all." As the only interviewee with an administrative background, participant #4 was the only physician to be able to speak in detail on nonprofit and for-profit labels as well as the shift towards more for-profit institutions. The other five physicians were "vaguely" familiar with the subject and could not speak on it "in detail."

Compared to family members of patients and physicians, a higher proportion of nurses were familiar with profit labels but were unable to discuss the shift from nonprofit to for-profit care. When I asked participant #11 if he knew what the difference between for-profit and nonprofit hospices was, he told me, "It's interesting that you ask that. Nurses are usually pretty familiar with that kind of thing because we often switch organizations. It's a good idea to know what kind of organization you're working for." Participant #1 responded in a similar way, "I've been a nurse for a long time. Hospice is pretty new to me, but I made sure I knew who I was working for." Turnover rate is a defining metric for retention rates in medical organizations. It is defined as the percentage of employees that leave a company within a certain period of time.[xliii] Data collected on resident nurse turnover rates in hospice facilities revealed a median rate of 28.6%.[xliv] To put this number in perspective, the median turnover rate for general medical care facilities was 18.4% in 2017.[xlv] The discrepancy is massive and is testament to the difficulty of working in the hospice industry and the high expectations placed on the work force.

Based on the qualitative data, basic knowledge of nonprofit and for-profit labels for hospice organizations is standard for both physicians and nurses. However, when it comes to privatization and the shift from nonprofit to for-profit hospice, most participants were unable to speak on it. This apparent lack of awareness about the current direction of the hospice industry in the United States demonstrates that there are gaps in the literature when it comes to the perspectives of hospice nurses and physicians.

Hospice-Wide Issues

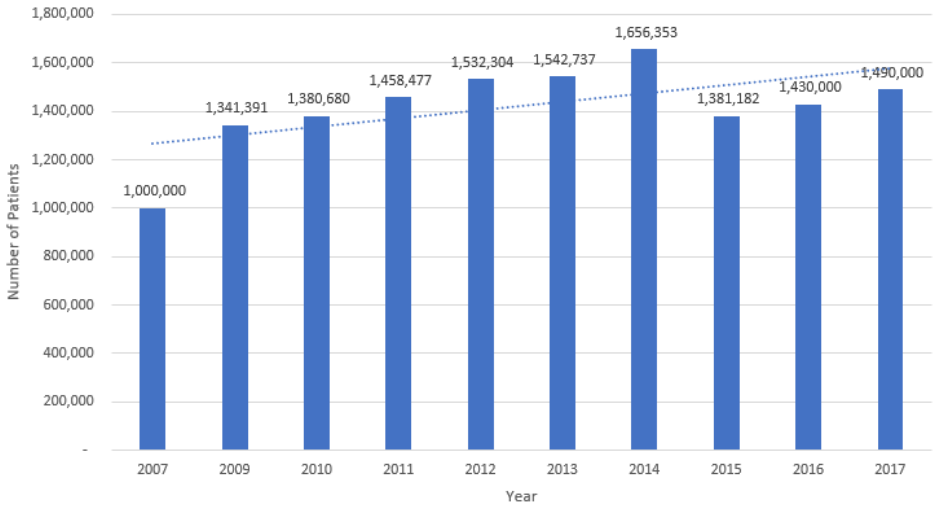
As referenced in the literature review, there are a multitude of issues that hospices struggle with: the emotional toll, understaffing, and the aging population. Understanding these industry-wide issues provides perspective on what obstacles face the 21st century hospice

employee. Interviewees were well-aware of these issues and admitted that they affected their decision-making in both their work and personal lives. A lack of success with addressing these problems certainly affects many hospice employees in their ability to care for their patients as well as for themselves. Participants expressed these concerns, regardless of hospice affiliation, because these are widespread issues that impact the entire hospice care industry.

All the interviewees could attest to the difficulty and stress of working in the hospice industry. In the interviews, there were a few common responses. First, they cited the sensitivity of their occupation. End-of-life care is a particularly emotional time for the patients and families who understand the likely outcomes. Navigating these emotions, satisfying distraught families, and providing quality care are all responsibilities of hospice staff. Participants alluded to high levels of anxiety and burnout. Participant #21 told me, “Hospice is different, and it’s really hard emotionally.” Autonomy was a word used to describe the responsibility of being a hospice nurse. Being quick on your feet and being confident in decision making were qualities that participants used to describe an effective hospice employee. Second, other participants referred to understaffing at their places of work as a source of stress. One said, “It’s not that they don’t try to hire people. Nurses just don’t last long in the position.” Another mentioned the growing US population and the impact that has had on increasing numbers of hospice patients. The aging population continues to grow and so does the number of sick patients. One said that hospices are struggling to keep up with the increasing demand for hospice care as nurses retire. The sentiment was that there are not enough new nurses to fill the gaps left in these institutions.

Finally, many participants referenced a lack of control around overtime hours and extensive caseloads. As previously mentioned, the US population is aging and, as a result, the number of adults seeking hospice care has increased.

Figure: Patient Growth



As the number of patients has increased, the number of hospice institutions has increased as well; however, the supply of hospice nurses and physicians has remained relatively stagnant. Throughout the discussion, these industry-wide issues will resurface.

Figure: Hospice Organization Growth

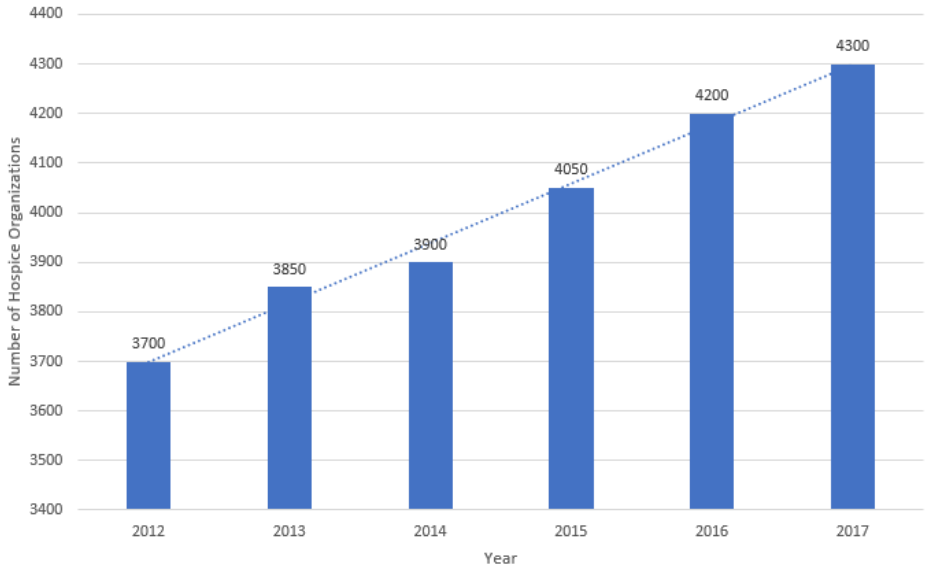
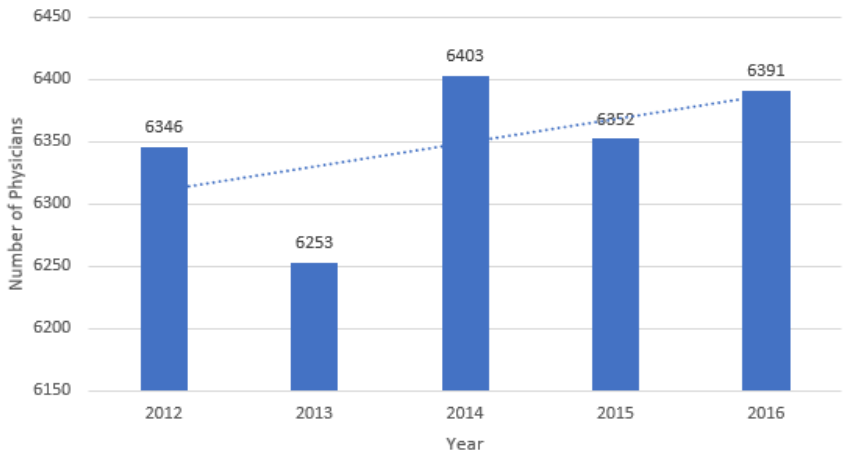


Figure: Physician Growth



Evaluation of Work-Life Balance

A nurse's or physician's work-life balance affects their ability to provide quality care as well as their personal well-being. For the purpose of this paper, "work life balance" is defined as a state of equilibrium in which the demands of personal, life, professional life, and family life are equal. It is an important aspect of any healthy working environment and can reduce stress while also preventing burnout in the workplace, especially one as rigorous as hospice. The importance of work-life balance is amplified in the hospice industry due to the high burnout rates and stress levels of working with fatally ill patients and distraught families. A poor work-life balance could negatively impact a nurse's or physician's ability to keep on top of their responsibilities and deliver quality care to their patients. On the other hand, a great balance leads to a healthier, more productive workforce. Over the last few years, the spotlight has shifted to highlight the importance of work-life balance in any workplace. Many see it as a company's responsibility to promote healthy lifestyles for their employees both physically and emotionally. Is this the case in hospice organizations? Does the balance vary between nonprofit and for-profit affiliated

institutions? To evaluate work-life balance, a multitude of factors were monitored: days worked per week, hours worked per week, hours worked per day, and type of case load.

For instance, participant #14 was a nurse at the Hospice of Kankakee Valley. She told me, “It can vary. It can go from usually 16 to, sometimes, it gets to be over 20. It’s supposed to be 20 weekly. It’s kind of how it goes. It depends on the level of acuity with them [the patients].” The unpredictability of hospice care is evident. Patients have different medical conditions which are dealt with in different ways. Despite the identity of the condition, nurses are expected to provide high quality care at the expense of their time and work-life balance. Participant #15 was in a similar situation to participant #14. In her organization, “We have a performance scale, and how often we see our patients is dependent on the number on that scale. If somebody is a 10, they are probably going to die soon and so that is somebody you are going to see every single day. So, you could have gone from seeing that patient once or twice a week to seeing them everyday on top of your regular patient load.” She described it best when she said, “It varies depending on the condition of the patient.” Other nurses faced the same struggles as participants #14 and #15. Although they are theoretically capped at seeing a certain number of patients per week, the number can inflate significantly from week to week. Participant #16 provided insight into the hospice nursing community. He told me nurses “help each other out when someone is loaded to heavily” and went on to speak positively about the support network that existed within the hospice care system. Looking at the responses of participants from nonprofit and for-profit hospice organizations, the averages are similar, and there are no significant discrepancies in nurse caseload, or the number of patients seen per week. However, this does not indicate whether the caseload in question is excessive.

When I asked participant #17, a nurse at Joliet Community Hospice Care, about the typical workday, she told me that she sees an average of six to eight patients during an eight-hour workday. She said, “It’s so hard because it’s such a different type of nursing. Like this weekend, I didn’t work but I work a weekend a month. You don’t see your regular patients on weekends. Weekends are primarily for people who are probably close to death.” Participant #17, a fellow nurse, echoed that sentiment, “The hard part is sometimes you’re squeezing all your people in a four-day work week [weekdays] because you get a day off during the week for that weekend.” Most of the nurses I spoke with mentioned similar systems in place at their hospice organizations, regardless of nonprofit or for-profit status. Participant #18’s life is a busy one. She told me, “Yes, sometimes you are rushed because you are shorthanded. You have a lot of nurses that are either off sick, or on vacation or their patient acuity is higher than yours.” She spoke of the high number of hospice patients compared with a lack of caretakers to look after them. Other participants agreed that they “probably” did not have the ability to spend as much time as they would like with their patients. But they still try to make the time to see patients for “at least an hour.” To deal with this issue, nurses rely on their colleagues as a support network. For example, a nurse whose patients are very high acuity, and thus require more care time, may be helped by another nurse whose patients are lower on the acuity scale. Despite their willingness to do so, hospice employees’ mission to provide quality care comes at the price of their own personal well-being and work-life balance. One nurse told me, “It comes at a price. You don’t work your regular workday and you’ll work over.” When asked if working overtime was a frequent occurrence, she said that it was. Another participant said, “The weekends are the worst. So, you’re supposed to work from 8am to 4:30pm but you tend to be out a lot later because staff is a lot less on the weekends.”

Participant #9 is a palliative physician at UCM and is responsible for working with many patients in hospice care. She told me her hours are standard at around 60 hours per week. Given that all the physicians interviewed were employed by UCM, the lack of variance in the collected data was expected. Participant #4, who was the physician with more administrative responsibilities, estimated her hours at 45 per week, which is an outlier in the dataset. Days worked per week were also standardized across all the physicians.

A rating to evaluate "work-life balance" is developed in this paper and is a key evaluator of the working conditions in the hospice industry. For the purposes of this dataset, "work wellness" is defined as the satisfaction level with work-only experiences. "Work-life balance" is defined as the satisfaction level with the balance between work and personal life.

Figure: WWR and WLB Data

	Nonprofit Hospice	**For-Profit Hospice**
Averages		
Work Wellness Rating (WWR)	7.2	7.6
Days worked per week	5.0	5.5
Hours worked per week	48	45
Hours worked per day	9.5	8.5
Work-Life Balance Rating (WLB)	7.0	6.5

WWR and WLB were evaluated on a simple scale of 1 to 10 with 10 being perfect.

In my conversations with nurses, the unpredictable work schedule, and the expectation to see the patients on the "list" has led to sacrifices on their end. Participant #19, who often must

work longer than the customary 8:30 am to 4:30 pm workday, said that she often has to bring administrative work home. She told me, “My work doesn’t end when I get home. I have to finish the patient notes.” Nurses and physicians are responsible for taking extensive patient notes, which are just as important as the patient interactions. Detailed and comprehensive notes help other caretakers understand what is going on with the patient and allow for a team-oriented approach to hospice care.

Organizational Focus

Organizational focus encompasses nurse and physician characterizations of their respective employers, current and former, in the hospice industry. Hospice websites are the definition of bias and paint the organizations that maintain them in an incredibly positive light. Participants gave a more realistic account of their experiences with each of these organizations.

Participant #20, a nurse at Hospice of Kankakee Valley, told me, “There is a hospice to hospice difference. There is a difference I notice with the hospice of Kankakee Valley as opposed to some other hospices. It is pretty much patient focused as opposed to other hospices, it’s all about productivity: you need to hurry up, get this done and over with.” Other nurses from the same organization also spoke very positively of Kankakee Valley and its dedication to “find solutions” and to be as helpful as possible to every patient. A “patient focused” hospice does not have set daily quotas and rather it is expected that patients are seen on a need-based system. For example, patients with more serious conditions would warrant more nursing time. Another participant added that at Kankakee Valley, nurses are expected to spend all their time seeing patients. There are no quotas to fill: if they finish early, they are expected to see additional patients. However, not all nonprofit hospices operate under the same rules and organizational priorities differ. Participant #18 is a nurse with experience at Hospice of Kankakee Valley and

JourneyCare, both of which are nonprofit affiliated hospice organizations. Yet, for her, the differences were "striking." She told me, "JourneyCare versus Hospice of Kankakee Valley, both are supposed to be not for profit. But, of course, JourneyCare is a much larger hospice organization. With Hospice of Kankakee Valley, they not only care about the patients but also their employees. But with JourneyCare, its more like do your job and whatever." This suggests that perhaps the labels placed on hospice are not indicative of work environments. In other words, hospice organizations cannot be generalized into two buckets: nonprofit and for-profit. These institutions are internally complicated and deserve increased attention to understand how we can address the problem of high turnover rates and low supply of hospice employees. A more comprehensive categorization system is required to understand the differences between hospice organizations and the missions that drive them.

Participant #21, a retired hospice nurse with over fifteen years of experience, characterized for-profit hospices in a worrying light. She has worked for several for-profit hospices including VITAS Healthcare and Chicago Hope. When asked to put into words her thoughts on the organizational focus, she told me, "VITAS is for-profit and my experience with them…has just been different from my time at nonprofit ones." However, other participants disagreed. Participant #4, a palliative care physician at UCM, is one of those with an opinion on the opposite end of the spectrum. She is well-aware of the distinctions between for-profit and nonprofit affiliations and, having had experiences and affiliations with both, does not see a clear distinction. She told me that the line between them is becomingly increasingly blurred: "My general feeling is that even not for profit hospices are moving more in the direction of either budget neutral or profitable hospices largely because the operating budgets are very, very constrained. I feel that the business model is changing in hospice care." Participant opinions

conflicted with one another, and the overall data was too varied to be suggestive of sweeping generalizations. But it is still insightful to see the broad range of opinions present within the same hospice industry.

To explore the conflicting results from organizational focus questions, participants were asked to describe the theoretical missions of nonprofit and for-profit hospices. Participant #16 told me that although literature categorizes hospices into nonprofit and for-profit labels, there should be no difference between them. Given the current collected data, the theoretical missions of for-profit and nonprofit hospice were described using the same descriptor words: “community driven,” “patient focused,” and “quality care.” This suggests that hospice affiliations should have no effect on the ability of hospice to provide high level end-of-life care to those in need. Quality of care is a standard that transcends organizational labels. Other participants mirrored this sentiment. Based on the interviews, the results were inconclusive given the spectrum of responses from participants. Some interviewees were convinced that there was a significant difference between working for a nonprofit hospice versus a for-profit whereas others said that the working conditions were relatively the same.

POLICY RECOMMENDATIONS

Much has been done in recent years to improve hospice care in the United States, and still more is being proposed. In 2010, the Patient Protection and Affordable Care Act was passed by Congress. One of its tenets required that state Medicaid programs allow children with life-limiting illnesses to receive both hospice care and curative treatment. In 2014, Congress passed IMPACT, Improving Medicare Post-Acute Care Transformation Act. Its main goal was to

standardize quality measures and data collection to make patient information more accessible. This enabled groups of physicians and caretakers from distinct hospitals to coordinate care plans to improve patient outcomes. More recently, as of February 2018, Congress and President Trump passed the Medicare Patient Access to Hospice Act. The new law allowed physician assistants to manage and provide hospice care to terminally ill Medicare patients: the first example of a law that addressed the issue of understaffing in hospice institutions. It did so by certifying more medical care workers to enter the hospice field. While this addresses the discrepancy between supply and demand, there is still more work to be done.[xlvi]

Based on the results from the qualitative study, there were a few key takeaways. The first is the diverse field of hospice organizations. There is currently no other way to categorize hospice organizations other than with the nonprofit and for-profit labels. However, the data suggests that these are not mutually exclusive categories. In terms of employee wellness, there is no distinct correlation between organizational status and work environment. Second, is the lack of awareness surrounding the hospice field and more specifically its privatization. Although privatization appears to have no significant impact on working conditions based on the results of this study, the lack of awareness speaks to ignorance about hospice among the general public. Third, and finally, is the unpredictability of work schedules for nurses and physicians. Hospice care employees do not know when their work schedules will turn stressful. It is all dependent on the conditions of their patients and the hospice's staffing situation. Due to the high turnover of employees in the hospice field, a poor work-life balance was expected and found in the results. While all three findings are significant, the third is the focal point for policy recommendations because it is directly related to workplace health.

A way to alleviate the uncertainty for hospice care workers is to look at the ever-growing lack of staff supply. The struggle to meet ever-increasing demands for hospice care is an uphill battle for both nonprofit and for-profit hospice organizations. The reality is, that today, there are not enough hospice employees, nurses, and physicians, to meet the growing demand from the aging US population. The supply of hospice employees that was acceptable 10 years ago is no longer adequate. Given current trends, this deficit will only grow worse. If the discrepancy in the ratio of hospice employees to patients is to be addressed and work-life balance improved, policymakers need to look abroad to other countries with more successful hospice programs.

The United Kingdom's Simultaneous Care Model

The United States is not the only country with the goal of improving end-of-life care for their citizens. Governments across the world aim to improve the availability, affordability, and quality of palliative care. The goal of palliative medicine is to comfort and treat people nearing the end of life. At the top of the rankings is the United Kingdom, Australia, New Zealand, Ireland, Belgium, Taiwan, Germany, the Netherlands and, finally, the United States.[xlvii] As the leader in quality hospice care, the United Kingdom has its own model for addressing hospice and palliative care throughout the country. The general idea is simultaneous care: providing palliative care services in parallel with treatment from other specialties. This model will serve as the basis for a policy recommendation.[xlviii]

The traditional view, that is still maintained in the United States, is that palliative care and hospice services apply only to those who are dying. Over the past decade, the United Kingdom has treated hospice care as an ongoing medical necessity that begins the moment a patient is checked into a hospital. According to Dr. Finley in the Journal of the Royal Society of Medicine, "Evidence that the cost efficacy of palliative care far outweighs attempts at disease

cure…has changed the emphasis in the UK towards services working parallel with other specialties, earlier in the disease."[xlix] Using cancer as an example, the United States would approach the care of a cancer patient with the traditional view. The patient would receive appropriate anti-cancer treatments such as surgery or chemotherapy. However, if the patient failed to improve and the medical outlook worsened, doctors would refer the patient to hospice for end-of-life care. There is a clear divide between the anti-cancer treatment phase and the palliative, terminal care phase. The United Kingdom's response to the same patient would be to provide anti-cancer treatments alongside palliative care until he or she recovered or passed away.[l] Rather than a clear divide, there is an obvious attempt to combine the two phases.

Nursing is the nation's largest healthcare profession with over 3.8 million registered nurses according to the American Association of Colleges of Nursing. In the United States, 54.7% of full-time employees in hospices are registered nurses.[li] The United Kingdom's view of palliative and hospice care shows promise in addressing the caseload issues raised by participants in the qualitative study. The United Kingdom's simultaneous care model suggests that hospitals be more involved in providing hospice care earlier in the patient's treatment plan. This corresponds to the involvement of more nurses in the monitoring of any given patient. As a result, this reduces caseload pressure on hospice specific nurses who can now rely on their general care colleagues to look after hospice patients, write notes, and ensure that care is proceeding appropriately. Input from this study's qualitative interviews identified administrative tasks like patient notes as one cause of stress and unpredictability. Increasing the overall number of nurses seeing a given patient reduces the administrative stress directly. This model is not complex either; in a hospital setting, it is common for patients with more severe conditions to be assigned more nurses and physicians. Application of this model in the United States, starting

with Chicago, will provide a support network, that adjusts depending on the acuity of the patient, for the hospice nurse to rely on.

The infrastructure for the model is already in place within the hospital, and it has the potential to reduce the unpredictability of hospice care work. As it is, hospice nurses in the Chicago area spend at least 50% of their patient visits writing notes on medications, treatments, and new developments. Participant #14 told me that oftentimes by the end of the regular workday, she would not be finished with these notes. She would then take them home and work on them during her personal time to ensure that the notes were comprehensive enough for other caretakers to understand the patient's condition. Implementation of the United Kingdom's model will create a larger support network for hospice physicians and nurses to rely upon for administrative help. The more caretakers that are responsible, the more notes there are to explain any given patient's condition. This leads to a greater source of information on the patient's condition if a new caretaker were to join the team.

Integrating the United Kingdom's model into the Chicago hospice infrastructure already in place is no simple task and will require years of development and overwhelming support from the government, hospice organizations, and legislative entities. One question that may arise is whether this model would shift more pressure onto general hospital nurses and physicians? Although this is a valid concern, it is important to consider the patient responsibilities that these individuals already have. While volume may increase, the palliative care of their patients still rests in the hands of the specialty specific nurses and physicians. General hospital employees can contribute to the palliative aspect of care by being present and by providing another set of eyes on the patient. That extra attention alone benefits both the patient and the hospice employees assigned to them. Encouraging the implementation of the simultaneous model will likely be a

welcomed force for change for hospice nurses and physicians affected by the unpredictability of their industry.

Increasing the Supply of Hospice Workers

The issue of understaffing in hospice care is a well understood and analyzed topic in modern literature. As of 2018, the United States has 13.35 hospice and palliative care specialists for every 100,000 adults 65 and older.[lii] Projections are just as worrying because the problem only worsens. Research estimates that by 2040, the aging patient population will need somewhere from 10,640 to 24,000 specialists. The supply of specialists is expected to range from 8,100 to 19,000.[liii] Stacie Levine, M.D., section chief of Geriatrics and Palliative Medicine at the University of Chicago Medical Center said, "There are many hospices across the country that are having very serious challenges recruiting and retaining physicians, nurses, and other staff."[liv] Participant #15 echoed Dr. Levine's stance, "It's not that they don't try to hire people. Nurses just don't last long in the position." Literature only strengthens the argument that more awareness is needed around hospice care. A 2018 study by RN Penny Alt-Gehrman concluded that the majority of medical and nursing students felt unprepared to provide high quality end-of-life care.[lv] These students are not exposed enough to the palliative specialty during their training and, as a result, hospices are finding recruitment difficult. Bethany Cox Snider, MD, vice president and chief medical officer for Hosparus Health said, "A big challenge that we face every day is that people do not understand this kind of work. They don't yet fully grasp the awesome, rewarding nature of this work because they have never touched it."[lvi] Much has been done on a small scale to address the lack of awareness surrounding hospice care. Individual hospice organizations such as Hosparus reach out to local clinicians and the community to educate them about what hospice care is and why it is so crucial as the American population ages.

Another relevant demographic is the medical students on the path to become physicians and who have the freedom to choose their specialties in the coming years. The question remains, even if exposed to palliative medicine, would medical and nursing students fill the gaps in the hospice workforce? Salary and lifestyle are factors in the specialty decision, but there is a notable lack of medical graduate training in palliative care. According to Head et al., "New doctors continue to report palliative care as the area in which they experience distress and feel unprepared. It is imperative that medical students are taught palliative competencies."[lvii] Those feelings are not conducive towards encouraging medical students to choose the field of palliative medicine. Increasing awareness in the public and volunteering spheres will ideally encourage future generations to consider the field of palliative medicine. Adjusting the medical and nursing school curriculums to include more exposure to palliative medicine will encourage medical and nursing students to consider a specialty that they might otherwise have not. These awareness changes will serve as the basis for a policy recommendation

There needs to be a national effort, starting with the state of Chicago, to educate the public and increase palliative care curriculums. The goal is to emphasize the importance of hospice care, what the words "hospice" and "palliative" mean, and the rewarding nature of the work. The first step is targeting hospice volunteering. Medicare law requires that volunteer hours equal at least five percent of the hospice provider's total patient care hours.[lviii] While this is already in place, hospice organizations need to highlight their volunteer programs. In Chicago, schools and universities are the perfect place to start. They are where the next generation develop, and these students represent the future of medicine and hospice care. Outreach could be in the form of emails to school list hosts, speakers at student gatherings, or connections with clubs and other student run organizations. Bethany Cox Snider, MD, summarized it well when

she said, “We were trained differently, and organizations need to step back and be willing to tailor their programs to the needs of [the future]. Because the reality is we need them. We need to get them into our industry or else there will not be enough staff to take care of people.”[lix]

Two future goals would be to lobby for change in current Medicare policy and open discussions with the Association of American Medical Colleges and American Association of Colleges of Nursing. For Medicare, a raise in the percentage of volunteer hours required, currently 5%, would encourage more contributions from volunteers. Medical and nursing school curriculums are always changing but remain centered around the core skills needed by any future medical worker. Beginning discussions to increase medical and nursing student exposure to palliative medicine would be a step towards increasing the supply of hospice workers. Progress does not need to be immediate and introducing structural changes like this is a long-term process. However, change starts on the state level and if it works, Chicago can be looked to as a role model for national change.

CONCLUSION

It is without a doubt that hospice care in the United States is becoming more privatized as nonprofit hospices continue to shift to for-profit status. The question that this thesis sought to answer was whether that privatization had an impact on hospice employee working conditions and well-being. Hospice is an area of medical care where those involved are exposed to high levels of emotion, autonomy, and stress. These sentiments are expressed by most of the participants in this study. Several key insights have arisen from this research. First, categorization of hospice institutions cannot be confined to nonprofit and for-profit labels. Collected data suggests that these are not mutually exclusive categories. In terms of employee

wellness, there is no distinct correlation between organizational status and work environment. Tax exemption status is not indicative of a positive or negative work environment. Nevertheless, there must be factors that correlate strongly with healthy work environments, and further research is needed to determine what those are. Second, there is lack of public knowledge about hospice care and lack of familiarity with its privatization. Although privatization appears to have no significant impact on working conditions based on the results of this study, the lack of awareness speaks to ignorance about hospice and privatization among employees and the general public. Finally, the study found that hospice nurses, particularly, are subject to schedule unpredictability. The hours are variable, and work often permeates into personal life which negatively impacts work-life balance. A poor work-life balance is one of the factors contributing to the stagnant supply of hospice employees. The results and insights from this study can be used to highlight and then address the industry-wide issues that affect the hospice community.

There remain millions of Americans who have no knowledge about what hospice and palliative care entail and, more importantly, how much it means for the future of America's older generations. More awareness means more people interested in potentially pursuing a career in palliative care. This means more nurses and physicians for hospices to hire, which would alleviate pressure that hospice employees endure on a daily basis. Taking care of our hospice employees is fundamental for the well-being of our patients and of our hospice community. The United States is getting older, and the population continues to age. Aging and quality hospice care have a direct relationship. Surging demand for hospice care correlates with a greater need for employees that can deliver it. Future projections indicate the need for more medical and nursing students to enter the fields of hospice and palliative care to meet the demand. However, recommendations and data alone are not enough to bridge the gap between supply and demand:

more needs to be done from a policy standpoint. The present times absolutely require more scrutiny on hospice care in the United States. Steps need to be taken to protect the medical staff that make it possible for us to have that extra time with our loved ones – every precious second.

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