DISPARITIES IN END OF LIFE PAIN: A PILOT STUDY IN HOSPICE

by

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Abstract

Cancer is one of the leading causes of death. Pain is one of the most common, feared, and distressing symptoms associated with cancer. Minorities experience more severe pain than non-Hispanic whites and are more likely to have their pain inadequately assessed and treated. Disparities in pain associated with cancer at the end of life are not well understood. This study sought to investigate the trajectory of cancer pain in those in an inpatient hospice facility and investigated disparities in nursing pain scores.

A retrospective chart review was conducted to collect the following data: demographics, cancer diagnoses, and nursing pain scores. Those with any type of cancer who died in the hospice facility were included. Descriptive statistics were used to describe the sample and high and low pain scores during the day shift. An independent t-test was used to examine disparities in nursing pain scores between whites and blacks.

Results from the study suggest those with cancer experience pain at the end of life, even when receiving optimal pain control in an inpatient hospice setting. Pain scores on the first 10 days after admission to hospice ranged from 0 to 10 with 20% reporting severe pain (pain scores 8-10) on the day of admission. Significant differences in mean high pain scores were found between blacks and whites on days 3 ($p= 0.010$) and 5 ($p= 0.032$). Results suggest pain continues to be a problem at the end of life in those diagnosed with cancer. Nurses must educate patients and families about pain goals in hospice and note that it may not be possible to achieve a complete absence of pain in this population.

Disparities in End of Life Pain: A Pilot Study in Hospice

Cancer is the second leading cause of death in the United States (U.S. Department, 2017). In 2018, approximately 1,735,350 people will be newly diagnosed with cancer and 609,640 will die from their disease (American Cancer Society, 2018). North Carolina is ranked eighth in the United States for cancer related deaths with approximately 20,380 cancer deaths per year (American Cancer Society, 2018).

Disparities continue to persist in the diagnosis and treatment of cancer. Minorities diagnosed with cancer are more likely to be diagnosed at a later stage, have decreased access to treatment, and experience lower survival rates (Vallerand, Hasenau, Templin, & Collins-Bohler, 2005; American Cancer Society, 2018). When insurance status, age, severity of disease, and health status are all similar, racial and ethnic minorities are more apt to receive lower-quality care than non-Hispanic whites (American Cancer Society, 2018). One of the goals of the U.S. Department of Health and Human Services (DHHS) Healthy People 2020 program is to achieve health equity, eliminate disparities, and improve the health of all groups (Healthy People 2020, 2010). Establishing goals related to eliminating disparities has been a part of the Healthy People initiative since the year 2000 (Office of Disease Prevention, n.d.). Recognizing and acknowledging the existence of health disparities is a means to the end of achieving high quality and equal health care for all patients.

Pain is one of the most commonly experienced symptoms after a diagnosis of cancer (American Cancer Society, 2018; Stein, Alcaraz, Kamson, Fallon, & Smith, 2016; McPherson, Hadjistavropoulos, Devereaux, & Lobchuk, 2014; McNeill, Reynolds, & Ney, 2007; Martinez, Snyder, Malin, & Dy, 2014; Green, Montague, & Hart-Johnson, 2009; Paice & Ferrell, 2011). It is estimated more than 75% of patients with an advanced cancer experience pain (Paice &

Ferrell, 2011). Pain can have tremendous effects on quality of life, endurance through treatment, health status after remission, and the ability to die peacefully (Paice & Ferrell, 2011). As stated by the National Institutes of Health (2002), pain is one of the most underreported and untreated symptoms associated with cancer. Both nociceptive pain, of the body tissues, and neuropathic pain, of the nerves, usually occur with a diagnosis of cancer. Commonly, patients with cancer will encounter pain that varies and becomes complex as the disease progresses (McPherson et al., 2014).

Disparities in cancer pain and pain management exist. Minorities report more severe pain than non-Hispanic whites (Green et al., 2009). Also, minorities are more likely to have their pain inadequately assessed and treated (Green et al., 2009). It is known that disparities exist in pain management (Meghani et al., 2014; Vallerand et al., 2005; Stein et al., 2016; Mossey, 2011; McNeill et al., 2007; Johnson, 2013; Green et al., 2009; Green et al., 2003; Anderson, Green, & Payne, 2009). Little is known, however, about possible disparities in the experience of cancer pain at the end of life. In a hospice facility during the last days of life, patients are more likely to receive scheduled analgesics and PRN medications (Hunnicutt, Tija, & Lapane, 2017). While we did not examine disparities within prescribed pain medication regimens, disparities in pain levels were examined. Knowledge gained from this study will address gaps related to health disparities and pain at the end of life in persons with cancer.

Review of Literature

Cancer Pain

Many symptoms are present with cancer, but pain is the most prevalent symptom (Green, Montague, & Hart-Johnson, 2009; National Institutes of Health, 2002). A quarter of patients report pain at the time of cancer diagnosis (Paice & Ferrell, 2011). Pain gradually increases as the disease progresses (McNeill et al., 2007). Cancer pain can be an effect of the cancer itself, treatment, diagnostic tests and procedures, or other present conditions (McNeill et al., 2007). Approximately 33% of patients experience pain while receiving treatment for their cancer (Paice & Ferrell, 2011). In cancer survivors, more than 30% of patients continue to report chronic pain (Paice & Ferrell, 2011).

Barriers to Cancer Pain Management

Several studies have shown multiple barriers to cancer pain management. One study conducted by Stein et al. (2016) identified barriers on the patient, provider, and system levels. The levels with the greatest disparities were the provider and system levels. Provider-level barriers included inadequate assessment of pain, reluctance to prescribe opioids, limited knowledge of pain management, and lack of communication skills. System-level barriers included resource scarcity or inequalities in the availability of analgesics in pharmacies and high costs of pain medications. Patient-level barriers were less significant in this study but can still be detrimental to effective pain management. These barriers include adequate communication, concerns and misconceptions regarding opioid addiction and side effects, fear of distracting physicians, medical mistrust, and belief that pain is inevitable (Stein et al., 2016).

Two additional studies identified barriers to pain management including: inadequate pain assessment, patient reluctance to report pain, inadequate staff knowledge of pain management, inadequate communication between physician and patient, physician mistrust, limited availability of pain medications in certain settings, and decreased health literacy (McNeill et al., 2007; Green et al., 2003).

The existence of barriers within pain management can be one of the causes of unrelieved cancer pain (Wilkie et al., 2017). In a study conducted by Wilkie et al. (2017), barriers to cancer pain management were reported by hospice patients and their caregivers. Barriers with the highest concern reported by patients included the notion that pain means disease progression and constipation from pain medicine. For caregivers, the top barriers to cancer pain management were pain means disease progression, constipation, addiction to pain medicines, and pain medicine causing confusion or one to do embarrassing things (Wilkie et al., 2017). The belief that pain is an uncontrollable companion of disease and addiction is unavoidable may result in nonadherence to pain medications and subsequent poor pain control (Wilkie et al., 2017).

Race Disparities

Disparities in health care can be defined as differences in the prevalence of diseases, health outcomes, and quality and access to care across racial and ethnic groups (Johnson, 2013). Many studies have explored these differences among racial groups in relation to cancer and pain management. Using qualitative interviews of black patients with advanced cancer, living with pain was one of the two themes that arose; with pain deriving from diagnosis, reoccurrence, treatment, and everyday life (Yeager, Quest, Vena, & Sterk, 2018). A study conducted by Im et al. (2007) supported the notion that ethnicity groups vary in their cancer pain experience. This finding has been shown in multiple studies that suggest black patients with cancer have higher rates of pain and suffering from symptoms than white patients (Vallerand et al., 2005; Martinez et al., 2014; Green et al., 2009).

Minorities diagnosed with cancer are less likely to be diagnosed at an early stage, receive prompt follow up after a positive screening test, and obtain initiation of proper treatment plans (Anderson et al., 2009). Moreover, physicians are more likely to underestimate reported pain levels in racial and ethnic minority patients (Mossey, 2011). Disparities also exist in analgesic prescription patterns. Black patients are more likely to receive a prescription for morphine rather than oxycodone for pain management, while white patients were the opposite (Meghani et al., 2014). Even after controlling for insurance status, black patients were still more likely to receive morphine over oxycodone (Meghani et al., 2014). A review of the literature by Mossey (2011) deduced that white patients receive more prescriptions for opioids at higher doses than blacks, Hispanic whites, or Asian Americans. Consistent documentation in research has shown inadequate treatment of cancer-related pain in minorities (Anderson et al., 2009).

Gender Disparities

Data is limited on gender disparities in pain and pain management. A survey conducted by Green et al. (2003) showed that women experienced more severe breakthrough pain than men, but these disparities were not consistent over time. Only one other known study has shown that women were more likely to report pain than men (Bernabei et al., 1998). There have been no known studies that investigate specifics of gender disparities in pain and pain management.

Age Disparities

Age disparities in pain and pain management is also an area with limited data. It is reported that 35-80% of nursing home residents encounter untreated pain (Green et al., 2003). Bernabei et al. (1998) conducted a study to evaluate the pain management of elderly and minority patients with cancer in nursing homes aged 65 and above. The results showed 26% of patients experiencing daily pain received no analgesics to relieve the pain. Out of these patients experiencing pain, as their age increased, the proportion of those who did not receive an analgesic drug also increased. For those that did receive analgesics for pain, patients that were older than 85 years received stronger opioids less frequently than patients in the 65 to 74 year category (Bernabei et al., 1998). There have been no other known studies since to research age disparities in pain management.

Rural/Urban Disparities

Also contributing to the gap in the literature is rural and urban health disparities. Pharmacies in rural areas may not carry medications because of fear of robbery or low demand, which causes low availability of needed medications (McNeill et al., 2007). In urban areas, disparities may exist due to restricted pharmaceutical formularies because of costs and agreements, limited physical space, and excessive mandatory documentation (McNeill et al., 2007). No known studies have been conducted to explore rural/urban disparities and pain at the end of life.

Summary

Cancer pain at the end of life can be extremely detrimental to the quality of life of some patients, to where it completely interferes with daily functioning (Vallerand et al., 2005). We know that almost all patients that are diagnosed with cancer experience pain, but not all pain is treated the same. While many patient, provider, and system barriers exist to hamper the pain management process, disparities may also exist due to demographic factors. Race, gender, age, insurance status, and residing in a rural or urban area may affect pain management. Current evidence supports disparities in cancer pain management, but relatively little is known about disparities in pain management at the end of life (EOL).

Research Aims

The purpose of this study was to examine potential racial disparities in nursing pain scores in patients with cancer in the final days prior to death. The specific aims for the proposed study were:

1) To determine the trajectory of pain during the first 10 days in hospice in a diverse sample with cancer enrolled in an inpatient hospice facility.

2) To examine race related disparities in nursing pain scores in a diverse sample with cancer enrolled in an inpatient hospice facility.

Methods

A retrospective chart review was conducted at a general inpatient hospice facility in the southeastern United States. A convenience sample of medical records were used. Those who were admitted to the facility after August 1, 2017 with any type of cancer diagnosis were eligible to be included. Those who were discharged to home or another facility while still alive were excluded. Patients who die in the inpatient hospice setting have pain closely managed by highly skilled nurses and physicians. Therefore, it can be expected these patients receive optimal pain management at the end of life.

Data was retrieved by a nursing student and a PhD prepared nurse. To ensure accuracy of the data, 20% of the data collected was reviewed by both researchers. Data retrieved included: age, gender, race, geographical location of residence, insurance status, and cancer diagnosis. Additional collected data included high and low pain scores for every shift during the patient's admission. Data was entered and stored in REDCap, a secure online data management system.

Pain scores are recorded by the nursing staff at various intervals during each shift as clinically necessary. To control for the variation in times pain was reported, the high and low pain scores for each day shift were recorded. When able, patients self-report pain scores to the nurse by ranking pain on a 0 to 10 scale. When patients are no longer able to self-report pain scores, nurses use the Pain Assessment in Advanced Dementia (PAINAD) Scale to determine the level of pain and record a number between 0 and 10.

The day shift was defined as 7:00 AM to 7:00 PM. Only day time pain scores were used in this analysis as this is when patients and hospice staff are most active. Zip codes retrieved from the medical records were used to determine if the person lived in an urban or rural county. The National Center for Health Statistics (NCHS) urban-rural classification for counties was used to organize counties. Counties classified by NCHS as large-central metro, large-fringe metro, medium metro, and small metro were considered urban counties. Counties classified as micropolitan and noncore were considered rural counties. Analysis of the data was conducted using descriptive statistics and an independent t-test.

Results

A total of 50 records were reviewed for this study (see Appendix A). The mean age was 63.92 (SD = 13.2) years and 46% of the sample was black. The majority of the sample was female (58%), resided in a federally designated urban county (58%), and covered by Medicare insurance (58%). Although all types of cancer were included, the majority of the sample was diagnosed with lung cancer (34.7%), breast cancer (16.3%), or head and neck cancer (10.2%). The average number of days spent in hospice was 4.94 (25th percentile = 1 day, 75th percentile = 7.25 days) days.

High and low nursing pain scores for day shifts were analyzed using descriptive statistics (see Appendix B). We analyzed high pain scores on the day shift for the first 10 days of admission. High pain scores on day shift ranged from 0 to 10 and low pain scores on day shift ranged from 0 to 10. While the general trend of pain at the end of life in hospice should be decreasing, the average high pain scores during the last shifts before patients' deaths increased (see Figure 1).

Mean high pain scores for the final five days of life were used to compare nursing pain scores between whites and blacks (see Appendix C). This range was selected because the majority of those included in the study were in hospice for 5 days or less (mean days in hospice

= 4.94 days). By day 5, only 26 participants were still alive. Significant differences in mean high pain scores were found between blacks and whites on days 3 (p= 0.010) and 5 (p= 0.032).

Discussion

This study was designed to explore the potential disparities that exist in nursing pain scores in patients with cancer at the end of life. We examined average high and low pain scores and conducted preliminary comparisons between blacks and whites.

Findings from this study indicate that even in an inpatient hospice facility, patients with cancer experience pain at the end of life. The high and low pain scores during the first 10 days of admission ranged from 0 to 10, meaning patients experienced moderate and severe levels of pain, even in an inpatient hospice setting. This supports previous findings by Paice and Ferrell (2011) that 75% of people with advanced cancer experience pain. The cause of this pain experience is unknown and could have multiple origins, whether patient-related or provider-related.

By day 5 of admission, only 26 participants were still alive, therefore, nearly half of the sample was not able to receive the full benefits of pain management in the inpatient hospice facility. This is concerning because 20% of participants rated their pain as an 8, 9, or 10 on the day of admission to the hospice facility. Due to such limited survival after admission neither the participant nor family is able to experience all the advantages that hospice care offers. An increase in survival after admission may decrease pain scores at the end of life.

Patients with all types of cancer were included in the study. This aids the results to be generalized to all cancer populations. The majority of the participants, however, were diagnosed with lung cancer (34.7%). In North Carolina, where the study population originated, lung cancer is estimated to be the highest diagnosed cancer with 8,490 new cases (American Cancer Society, 2018). It will also cause the most cancer-related deaths with 5,770 deaths (American Cancer Society, 2018). Study results align with regional trends in lung cancer diagnoses and deaths.

With the significant findings from the t-test analyzing average high pain scores in whites and blacks, it is possible that cancer pain may be experienced differently by blacks. This concurs with the findings of studies previously conducted (Meghani et al., 2014; Vallerand et al., 2005; Stein et al., 2016; Mossey, 2011; McNeill, Reynolds, & Ney, 2007; Johnson, 2013; Green et al., 2009; Green et al., 2003; Anderson, Green, & Payne, 2009). However, this study is the first known quantitative study to investigate cancer pain at the end of life in such a diverse sample. Black patients comprised 46% of this study sample. Pain is the most prevalent experience that accompanies a cancer diagnosis and minorities experience many disparities in relation to this pain and the cancer itself. It is outside the scope of this study to determine the reasons for disparities in pain scores at the end of life. There may be differences in patient or nurse reports of pain, differences in prescription practices or the administration of analgesic medications, or biological differences that contribute to these disparities.

Limitations

One limitation of this study was the retrospective design. Data was limited to what was recorded in the medical record and data that was missing could not be retrieved. Additionally, pain is subjective and ideally should be reported by the patient. When patients are alert, oriented, and verbal, subjective pain scores are achieved. When approaching death, sedation increases, and pain scores become objective; the nurses then score pain based on nonverbal indicators. Subjective pain scores reported by the nurse may not be as accurate as patient pain scores.

While the study can be generalized to patients experiencing cancer pain, it cannot be generalized to those encountering non-malignant pain. Only patients that had a cancer diagnosis were included in the study. Pain experienced by those in hospice who do not have cancer was not examined. Therefore, this study cannot be generalized to those with non-malignant pain at the end of life.

Another limitation of the study was the high number of persons who died soon after admission to hospice. Nearly half of participants were deceased after 5 days in hospice. This study was not able to examine the pain experience of those participants in the days prior to enrollment in inpatient hospice and data was often limited to 1 or 2 day shifts. This does not fully capture the experience of pain at the end of life.

Clinical Implications

Due to the findings of ongoing prevalence of pain in the final days prior to death, the absence of pain may be an inappropriate goal to set for patients. Nurses should begin to educate and thoroughly discuss pain goals with patients and families at the time of admission. Nurses should continue to provide comfort measures, but setting a goal to keep pain at a minimum, while still achieving goals for sedation, may be more appropriate. Finally, nurses should advocate for enrollment in hospice when it becomes appropriate to increase survival after admission and to provide patients and families with the opportunity to experience the full pain management benefits of hospice.

Future Research

More quantitative studies examining pain at the end of life in such diverse samples are needed. Exploration of the possible difference in pain experience in minorities should be studied to determine why these disparities were found. Also, studies examining pain in relation to sedation scores are needed. As sedation increases, pain control becomes more reliant upon nursing assessments of pain. Adequate pain control is difficult to determine when the person can no longer self-report pain.

Disparities and pain in patients with cancer could be further examined in hospice facilities in different geographical locations. Variations in the results may occur if studies similar to this one were conducted in areas with different populations. Pain experienced by patients without cancer diagnoses could also be studied to identify further possible disparities. Intervention studies are needed to address identified disparities in pain in this population.

Conclusion

Maintaining comfort and alleviating pain at the end of life is the primary goal in hospice patients and their families (Hunnicutt, Tija, & Lapane, 2017). Nursing pain scores in this study suggest patients continue to experience severe pain at the time of admission to hospice and in the final days of life. The absence of pain may not be a realistic goal in this population. Disparities in pain scores at the end of life indicate a need for further investigation into the reasons for these disparities and interventions are needed to eliminate disparities in pain.

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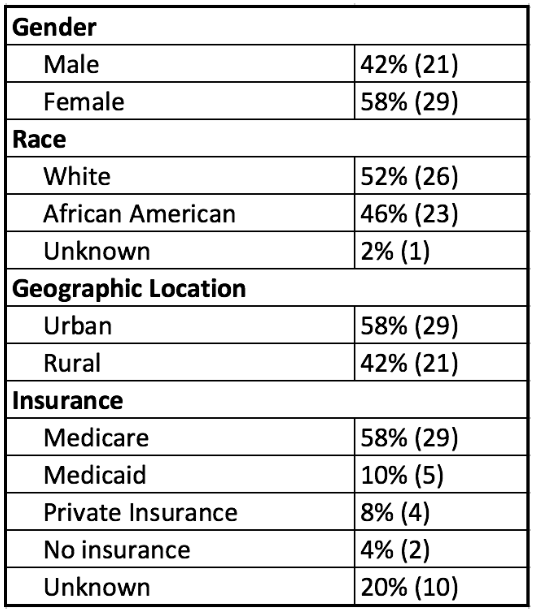
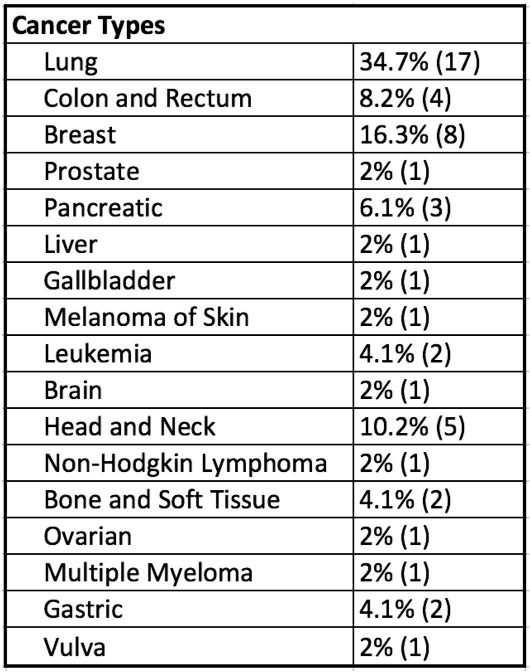
Appendix A



Gender	
Male	42% (21)
Female	58% (29)
Race	
White	52% (26)
African American	46% (23)
Unknown	2% (1)
Geographic Location	
Urban	58% (29)
Rural	42% (21)
Insurance	
Medicare	58% (29)
Medicaid	10% (5)
Private Insurance	8% (4)
No insurance	4% (2)
Unknown	20% (10)

Table 1A. Study Demographics.



Cancer Types	
Lung	34.7% (17)
Colon and Rectum	8.2% (4)
Breast	16.3% (8)
Prostate	2% (1)
Pancreatic	6.1% (3)
Liver	2% (1)
Gallbladder	2% (1)
Melanoma of Skin	2% (1)
Leukemia	4.1% (2)
Brain	2% (1)
Head and Neck	10.2% (5)
Non-Hodgkin Lymphoma	2% (1)
Bone and Soft Tissue	4.1% (2)
Ovarian	2% (1)
Multiple Myeloma	2% (1)
Gastric	4.1% (2)
Vulva	2% (1)

Table 2A. Types of Cancer Diagnoses in Study Population.

Appendix B

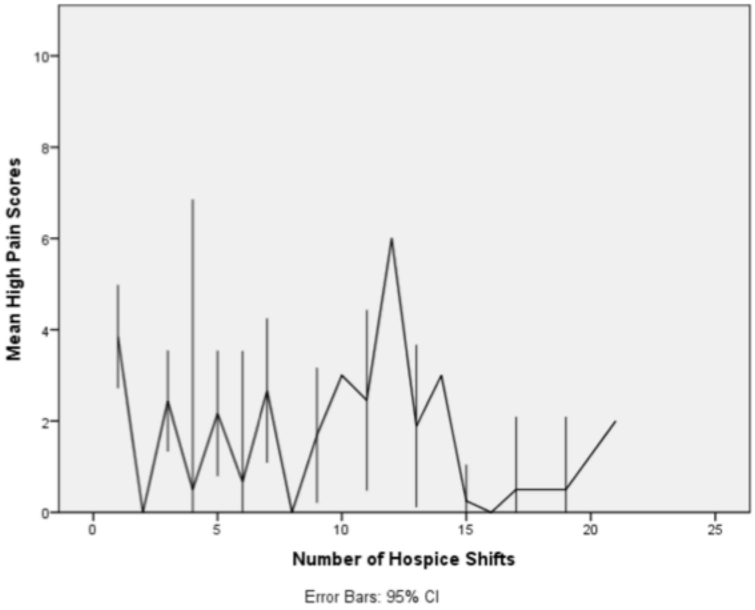


Figure 1. Mean High Pain Scores. This figure shows the average high pain scores for all patients on day shifts. The vertical lines represent the range of pain scores for the shift.

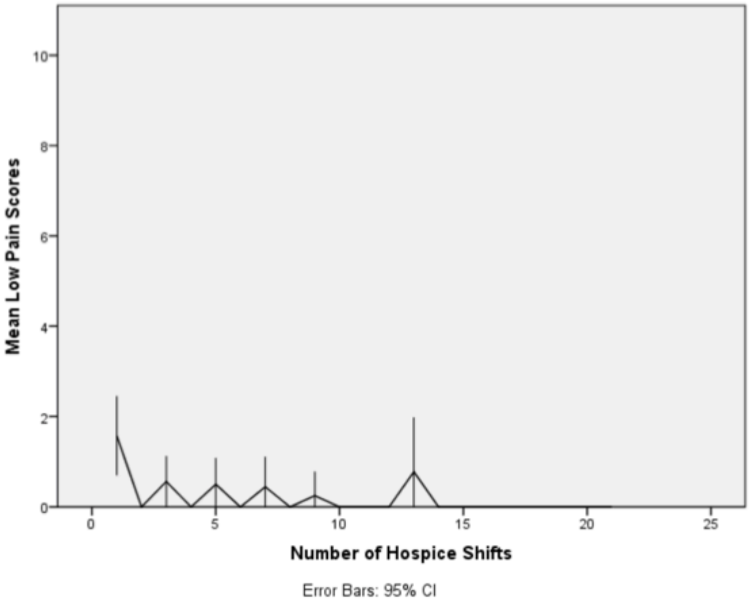


Figure 2. Mean Low Pain Scores. This figure shows the average low pain scores for all patients on day shifts. The vertical lines represent the range of pain scores for the shift.

Appendix C

Day Shift	**1**		**2**		**3**		**4**		**5**	
Mean Pain High Score	3.76		2.1		2.29		1.73		2.08	
IQR	0.00	7.00	0.00	4.00	0.00	3.00	0.00	2.50	0.00	3.00

Table 1B. Mean Pain High Scores and Interquartile Ranges for First 5