

Understanding Policies and its Effects on Hospice and Palliative Care

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Abstract

This paper explores how the level of knowledge in hospice and palliative care nurses concerning policy affects patient care. A literature review was conducted to determine how the level of policy knowledge influences various patient outcomes. This review focused on four main areas, including pain administration at the end of life, hesitancy to report errors, nonadherence to legislation and policy, and the impacts of moral distress. In addition to discussion concerning patient outcomes, this paper addresses education and other clinical practice recommendations to improve patient outcomes related to the four main areas of this paper.

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Background

The policies that govern healthcare are involved and complex. Nurses provide direct patient care, making it imperative that they understand the policies that govern nurses and their organizations. Healthcare policies are constantly changing and evolving to keep up with changes in technology or other relevant issues in the healthcare field. The guidelines and regulations that result from changes in legislation and policy have a profound impact on the nursing role and the care nurses are able to provide. Lack of knowledge about regulation and policies can lead to confusion for all parties involved. This may ultimately lead to policies not being followed and bring about legal consequences or patient harm. The ultimate goal in patient care, is to prevent patient harm and promote health. In the hospice and palliative care settings, the goals of care differ from goals in the acute care setting. In hospice care, goals are no longer centered around curing the patient. Instead, they are centered around promoting quality of life. In hospice care, patients are no longer receiving curative treatment for their illness, whereas in palliative care, patients may continue receiving treatment while receiving comfort care (NIA, 2021). Policies in these specialty areas may be different than in other areas of healthcare in order to help effectively meet patient goals at the end of life.

According to the National Institute on Aging (NIA), people are increasingly choosing to receive hospice care at the end of life, as care focuses on comfort and quality of life, empowering patients to die in their preferred manner (NIA, 2021). The NIA also states that hospice patients are more likely to have their pain under control and undergo less testing which they may not require, as they have decided to no longer pursue curative treatment (NIA, 2021). In order to accomplish these goals of hospice patients, nurses have to be aware of policies that may affect

patient goals, including policies about opioid administration at the end of life, reporting adverse events, and adhering to agency policy. Unfortunately, this understanding and awareness is not always present, and patients receive care that is not consistent with their end-of-life goals.

Because of the numerous policies and regulations hospice and palliative care nurses must adhere to, it is important to understand how knowledge of these policies may affect not only the nurse providing care, but the patients receiving it. To gain this understanding, a literature review was conducted to address the following research question: How does the level of knowledge in hospice and palliative care nurses concerning legislation and policy affect patient care? This review uncovered four main areas in which lack of policy knowledge may affect patient care. These areas include pain administration at the end of life, reporting hesitancy, nonadherence to policy, and moral distress.

Methods

A literature review was conducted to help determine how the level of knowledge concerning healthcare policy affects patient care. Literature was pulled from various scholarly databases, including Cochrane Library, PubMed, and CINAHL Complete. Keywords implemented throughout the search included hospice, palliative care, policy, regulations, nurses, and patient care outcomes. After viewing the results from the initial literature review, further searches were refined to include the following terms: pain, reporting, nonadherence or policy noncompliance, and moral distress to further investigate the four main areas that were identified to impact patient care. Qualitative and quantitative studies were both included in the review.

Literature Review

Pain Medication Administration at the End of Life

Pain control is an important patient goal at the end of life. In fact, evidence shows that uncontrolled pain has adverse effects on patients. It alters their ability to perform their activities of daily living, may negatively affect their relationships with loved ones, impairs their ability to communicate, and may exacerbate anxiety at the end of life (Taylor, 2015). Despite this, evidence shows that nurses may be hesitant to administer pain medication at the end of life for various reasons. A study by Willmott et al. in 2020 found that many palliative care and hospice nurses perceive inadequate pain control and pain relief to be a massive issue at the end of life. These nurses think that pain is not properly addressed, resulting in poor patient outcomes. The nurses stated that they had seen unmanaged pain outcomes range from mild patient discomfort to extreme agony that burdened the patient and their family members. Despite this, these nurses reported that they were hesitant to administer medications, as they feared repercussions such as being held accountable if a patient were to die from opioid administration or having to face angry family members (Willmott et al., 2020). These fears also included facing Coroner's Court, criminal charges, or civil litigation due to hastening patient death with opioids or sedatives.

Even though this study found that many of the nurses' fears were based on hypothetical scenarios or stories of other nurses facing legal repercussions, their individual nursing practice was heavily influenced by these concerns. Some of the ways these concerns revealed themselves in clinical practice involved the under-reporting of signs and symptoms of patient pain, the under-administration of pain medications, and the over-documentation of medication administration to the patient. All of these factors ultimately lead to patients having poorly managed pain (Willmott et al., 2020). This study highlighted the fact that these nurses were unaware of their legal protections concerning opioid administration at the end of life and were more likely to withhold pain medication due to this lack of knowledge and fear of hastening

patient death. A subsequent study conducted by Willmott et al. specifically found that the nurses lacked knowledge about the legal principles of the doctrine of double effect, which will be further explained shortly. In this small study, twelve out of twenty-five nurses understood the doctrine of double effect, while nine nurses had “no clue” about how this doctrine impacts their practice (Willmott et al., 2020). The authors specifically stated that these “nurses did not understand that they were protected by the law” (Willmott et al., 2020). Although nine nurses may seem like a small amount to be concerned about, it is important to consider how this is relevant to real practice. Often, nurses are in charge of the care for multiple patients. If each of these nine nurses had five hospice patients, it could mean that forty-five patients may have inadequately managed pain at the end of their lives, decreasing their quality of life.

The doctrine of double effect is used internationally as a legal defense in the United States of America, Australia, the United Kingdom, Canada, and New Zealand. This doctrine acknowledges that the administration of some medications may “incidentally hasten death” (Willmott et al., 2020). Despite this, the doctrine states that it is lawful to administer these medications so long as the intent of administration is explicitly to relieve patient symptoms and not to hasten death (Willmott et al., 2020; Wholihan & Olson, 2017). Similarly, the doctrine of double effect also acknowledges that opioid administration and palliative sedation may be the only way to keep a patient comfortable at the end of life. Furthermore, this may mean keeping a patient sedated until death if doing so honors their wishes and comfort goals at the end of life (Wholihan & Olson, 2017).

However, according to Wholihan and Olson (2017), evidence shows that appropriate use of opioids and palliative sedation does not shorten life or hasten death. Nevertheless, nurses are still concerned about the consequences of patient death under their care (Wholihan & Olson,

2017). This doctrine also applies to the discontinuation of foods, fluids and other medications, which are often stopped toward the end of life. The doctrine of double effect also provides a legal defense so long as opioids and sedatives are used at the lowest dose required to achieve relief of symptoms (Wholihan & Olson, 2017). Both Wholihan and Olson, and Willmott et al. argue that understanding this doctrine leads to better patient pain management. However, they also agree that there is not an adequate level of current understanding of this among nurses. A study conducted by Bosshardt et al. helps illustrate this lack of understanding. The study found that 5.3% of nurses (in their study of 2000 nurses) believed that increased opioid and sedative doses at the end of life would hasten death (Bosshardt et al., 2018). This means roughly 106 nurses in their study believed they could hasten death by administering opioids, and most likely were not adequately managing their patients' pain. As mentioned previously, each of the 106 nurses were likely caring for multiple patients. If each nurse had five patients, roughly 530 patient lives have the potential to have poor outcomes due to unmanaged pain because these nurses do not have an adequate understanding of their legal protections based on the doctrine of double effect.

Reporting Hesitancy

The second area in which nurses' level of knowledge affects patient care is in the reporting of noncompliance with organizational policies and/or adverse events. There are many reasons why nurses may be hesitant to report noncompliance or adverse events. One of these reasons is that nurses may feel that their concerns may be ignored. Unfortunately, this is a very real possibility. For example, a nursing home chain in California faced legal consequences due to noncompliance with staffing regulations. The Centers for Medicare and Medicaid Services (CMS) and state standards dictate that there must be enough staff to adequately care for the

residents in the nursing home (Harrington et al., 2014). Nurses in this facility had constantly submitted reports concerning the lack of staff to their superiors. However, the staff was ignored, ultimately contributing to the organization facing litigation (Harrington et al., 2014). In a similar situation, nurses attempted to report a doctor for unethical behavior. The doctor had withheld the patient's prognosis until within twenty-four hours of the patient's death, which was concerning to many of the nurses. When the nurses attempted to get the ethics committee involved they were "told to mind their own business and stay out of the situation" (Bosshardt et al., 2018).

Many nurses may also not be aware that their organizations have policies protecting employees from retaliation for reporting. However, even if they are aware, many of them still fear retribution from their peers and colleagues - especially if they do not have a confidential reporting system (Cole et al., 2019). A study by Cole et al. in 2019 found that approximately 20 percent of nurses answering a question about why they are afraid to speak out cited they were afraid to do so because they feared retaliation. In addition to this, the survey responses suggest that many nurses have not personally experienced retaliation when reporting but knew of other nurses who did. This promoted a culture of fear around reporting (Cole et al., 2019). This is significant, as when nurses do not report or speak out about adverse events, unethical behavior, or unsafe practices, it allows negative behaviors to perpetuate.

Nurses may also not report adverse events if reporting is not confidential as some may believe that systems like this encourage lawsuits (Wolf & Hughes, 2008). However, Wolf and Hughes found that reporting and disclosing errors, especially to patients, is important for patient and healthcare provider outcomes. They emphasized that "when providers tell the truth, practitioners and patients share trust" (Wolf & Hughes, 2008). This illustrates that not reporting adverse events, whether due to lack of knowledge concerning organization protection policies or

fear of retaliation, leads to decreased patient trust. This is especially true when healthcare workers attempt to cover up their mistakes.

When cover-ups are revealed, it results in patient mistrust and adversarial relationships between the patient and their healthcare providers (Wolf & Hughes, 2008). Wolf and Hughes found that patients want full disclosure in a timely manner when it comes to errors in their care. They also found that truthful reports of errors may actually result in greater patient trust and decreased chances of litigation (Wolf & Hughes, 2008). These studies indicate that when nurses do not have knowledge about their policies, and therefore do not believe they will be protected against retaliation, they are less likely to report which may lead to negative patient experiences. Wolf and Hughes state that it is important to report even near-misses in patient care, as it helps identify places that need to be improved in order to promote patient safety (2008). Therefore, failing to report may result in the behavior continuing, leading to policies continuing to be violated and patients continuing to be harmed.

Nonadherence to Legislation and Policy

Nonadherence to legislation and policy by nurses or their organizations, whether out of ignorance or apathy, has profound consequences on patient outcomes. There are times when consequences of violations may occur unintentionally. For example, the trade journal *Hospital Access Management* published an article in 2020 about a small clinic failing to conduct risk analysis and implement risk management control to protect private patient information. Depending on the facility, a nurse may be in charge of, or involved in, the department responsible for conducting risk analysis. Because a risk analysis wasn't done, it contributed to a systemic vulnerability that led to patient information being put online for sale by outside entities, violating the Health Insurance Portability and Accountability Act (HIPAA). This ultimately led

to a \$1.5-million settlement (Ongoing noncompliance leads to serious settlement for small clinic, 2020). If nurses (or in this case, an organization) do not know about the policies that regulate them, this may lead to patient information being revealed without consent. The reason for this settlement, was that the organization failed to meet the minimum standards needed to be HIPAA compliant over time. However, that is just one form of patient consequences that may occur with nonadherence to policy.

Knowledge of policies allows nurses and organizations to be compliant with them. Compliance in long term care facilities has been shown to be associated with positive outcomes in the following areas: “functional ability, pressure ulcers, weight loss, deficiencies, and other measures” (Harrington et al., 2014). Many hospices and nursing homes are regulated by the Centers for Medicare and Medicaid Services (CMS). One of the standards put out by CMS includes adequate staffing. One of the examples Harrington et al. talked about in their article, was that inadequate staffing in a large nursing home chain led to negative patient outcomes and patient harm – ultimately resulting in 667 million court assessed damages (2014). The patients in these understaffed facilities experienced harm because of a lack of nurses, and the resulting inability of nurses to adequately provide patient care. One patient had three falls with a hip fracture while another patient had a stroke that went undetected for two weeks. Pressure ulcers in the facility were not properly treated, resulting in some patients having to undergo amputations. One patient with dementia wandered out in a storm and later died from hypothermia (Harrington et al., 2014). This was not the fault of the nurses; it was the organization choosing noncompliance with regulatory standards. This organization only faced fines. However, noncompliance by staff and the organization itself, knowingly or unknowingly, can lead to shut down, which has even more profound patient impacts.

Before nursing homes and hospices are shut down, they will most likely be terminated from CMS certification status. This is because federal certification status is used as a powerful tool for quality enforcement (Li et al., 2010). CMS regulated facilities may voluntarily terminate themselves from CMS certification, and lose CMS reimbursement, or these facilities may be involuntarily terminated due to noncompliance to policies – whether at an organizational level, or if enough nurses or other staff are not complying with policies to have a major impact (Li et al., 2010). One example of this took place in Buffalo, Wyoming. In this case, a facility committed fraud by misrepresenting services rendered and falsely billing the Wyoming Medicaid Program. This resulted in the facility being withheld from membership certification for a year in 2016 (Rao, 2020). When noncompliance by staff members results in institutions being terminated from CMS certification, Medicare and Medicaid patients are required to be relocated to another facility, whether they are regular residents, rehab patients, or hospice patients. This relocation increases family burden and the risk for adverse patient outcomes due to the move and the unfamiliarity of the new facility (Li et al., 2010). A study by Weaver et al., in 2020 provides further support for the negative patient outcomes that occur when patients have to be relocated. These authors found that residents with higher cognitive function were actually more at risk for negative outcomes during the relocation process. Patients who were to be relocated expectedly experienced higher levels of stress before and after the move due to grief, fear that they would lose “personhood”, and the loss of friendships between residents as well as residents and their caregivers (Weaver et al., 2020). Although relocation was not associated with increased mortality rates, residents had increased functional and psychological changes after the move. However, they tended to return to baseline status over time (Weaver et al., 2020).

It is important to note that these were the long-term results for residents of nursing homes. Hospice and palliative care patients in these facilities do not have the same amount of time to make these adjustments back to baseline. It can be assumed that relocation at the end of life for a hospice patient is extremely detrimental to the patient and their family. If this is a stressful occurrence for patients with a longer expected lifespan, it may be even more stressful to the patient and family that has a life-limiting illness. Termination from CMS, voluntarily or involuntarily, due to regulatory noncompliance by nursing staff or the organization itself, forces the relocation of residents, which results in negative patient outcomes. End-of-life patients most likely experience these negative outcomes more acutely.

Moral Distress

There are many instances in which nurses may experience moral distress. This often happens when nurses are conflicted about the care being provided (Wholihan & Olson, 2017). While moral distress deeply affects nurses, it also may affect patients negatively. Bosshardt et al. state, “When nurses do not feel empowered to speak up for behalf of their patients and therefore remain silent, it results in not only moral distress but also patient harm” (2018). These same authors also point out that they found higher levels of moral distress among nurses, such as hospice and palliative care nurses, who may be giving “futile” care. Bosshardt et al. defined “futile” care as “the continued provision of medical care or treatment to a patient when there is no reasonable hope of cure or benefit” (2018). These authors identified other sources of moral distress. Some examples include inadequate staffing – which led to less time to provide comprehensive patient care and promote safety – and doctors providing false hope to dying patients (Bosshardt et al., 2018). During this study, nurses were required to wait for doctors to discuss end of life care with their patients. However, because the doctors were attempting to treat

patients and providing them with false hope, these conversations often did not occur until days or weeks before the patients' deaths, causing them unnecessary pain and discomfort (Bosshardt et al. 2018). This, in particular, caused increased levels of moral distress among nurses at this facility and resulted in negative patient outcomes.

There are some cases in which having a good understanding of policy may lead to moral distress in nurses and negative patient outcomes, contrary to what has been discussed in previous sections. One example is a study that took place during the height of the COVID-19 pandemic. Visiting restriction policies, as well as care facilities refusing COVID positive patients, led to many patients' end of life wishes not being honored, thus increasing moral distress in nurses (Bradshaw et al., 2022). This also resulted in higher levels of moral distress among nurses who watched patients die without their family present (Bradshaw et al., 2022). This same study illustrated that nurses were concerned their patients with more complex needs were not receiving the support they required due to COVID-19 policies. Some of these policies included not being able to make in-person visits to patient homes that required home care assessments, being prohibited from admitting patients that needed aerosol-generating procedures, and infection control procedures leading to dilution of services, in addition to the previously mentioned visitation restrictions. Many services were suspended, adapted, done remotely, or done with isolation equipment, which took away some of the personalized aspects of care (Bradshaw et al., 2022). The buildup of enduring so much psychological, emotional and physical harms due to the repeated exposures to moral distress resulted in what Bradshaw et al. refer to as "moral injuries" (2022). The consequences of moral distress and injury are best illustrated by Bradshaw et al. (2022) when they state:

If the impacts of moral distress are sustained without being recognized or dealt with appropriately, it can decrease the capacity of health professionals to deliver high quality care, lead to burn out, and increase the likelihood of staff making errors and leaving roles. The consequences of moral distress are not new. For example, in 2017, Kavalieratos et al. found that moral distress was linked to increased burnout which, in turn, is linked to an increased risk of medication errors. In their study, they also found that burnout led to nurses experiencing apathy and detachment from their patients. This resulted in impaired empathy, decreased engagement and decreased quality of care (Kavalieratos et al., 2017). It is also important to note that burnout in hospice and palliative care healthcare workers is among the highest compared to other medical specialties (Kavalieratos et al., 2017). Moral distress and burnout being high in healthcare workers in this specialty also means that there is a higher risk of negative patient outcomes.

Clinical Relevance

The knowledge of hospice and palliative care nurses concerning policies does have an effect on patient care. Lack of knowledge concerning policies was shown to have adverse patient outcomes as evidenced by decreased pain management at the end of life, decreased patient trust when errors were not reported or disclosed, negative patient consequences when policies are not followed, and impaired connections with nurses in moral distress. This literature review helps illustrate that hospice and palliative care nurses are at risk of inadvertently causing negative patient outcomes when they do not have the knowledge about policies needed to provide quality care to patients. Based on the results of this review, and on the suggestions of various authors throughout the study, more education and research are needed to help address these concerns and improve patient outcomes.

When addressing knowledge deficits concerning legal knowledge for pain management, Willmott et al. state, “More education is urgently needed to strengthen nurses’ legal understanding and help them feel more confident when providing care to their patients at the end of life” (2020). They recommend using workshops and online programs to help educate nurses, and further research. Wholihan and Olson (2017) recommend not shying away from ethical discussions and learning to openly acknowledge and discuss the complexity of end-of-life care. Similarly, Taylor (2015) emphasizes the fact that nurses should be aware of and be able to confidently manage the legal and ethical issues that arise when caring for patients at the end of their lives, if they are to help the patients “die a good death”. To address reporting hesitancy, Cole et al. (2019) suggest education and training concerning the benefits of reporting and embedding safer practices in to care. They also advocate for promoting a safe culture, allowing for respect and blame-free communication opportunities. To do this, they recommend also taking time to educate leaders and to refine reporting systems through further research (Cole et al. 2019). In regards to reporting hesitancy, it may be beneficial to implement an anonymous and confidential reporting system to address concerns highlighted by Wolf and Hughes (2008). Kavalieratos et al. (2017) urge further research into interventions that address and prevent moral distress and burnout. When looking back on the litigation cases for noncompliance, the lesson to be learned is that nurses and organizations should keep up with new regulations set out by regulating agencies, as each organization will be held responsible for their personal compliance.

Discussion

The research conducted throughout this review shows that lack of knowledge concerning policies and legislation is a real issue among hospice and palliative care nurses, leading to unmanaged pain, adverse events not being reported, systemic noncompliance, and moral distress.

This review found many cases in which lack of policy knowledge resulted in decreased patient outcomes, such as in the administration of medication at the end of life. Another example is with reporting hesitancy and noncompliance. As mentioned previously, various authors have stated that more education regarding policies has the potential to address these knowledge deficits and hopefully result in better patient care outcomes at the end of life. More research in these areas should be conducted to conclude the accuracy of these claims and to determine interventions that may be effective in improving patient outcomes.

Another potential area of research is to see how the consequences presented in the situations presented in this literature review affect moral distress in nurses. Because moral distress in nurses is shown to have adverse patient outcomes, there is a possibility that moral distress in those situations could have contributed to the various negative patient outcomes rather than solely lack of knowledge concerning policy. It is not possible to tell how much moral distress contributed to inadequately managed pain, errors not being appropriately reported, and policies not being followed in this literature review. Researching the effects of moral distress on the three categories mentioned may yield further clarification to the results found in the literature review.

Although much of this literature review illustrated that lack of policy understanding contributes to negative patient outcomes, it is important to recognize that knowledge of policy does not always lead to improved patient outcomes. The study conducted by Bradshaw et al. showed that knowing the COVID-19 related policies actually increased moral distress in nurses, which increased the risk for patient harm (2022). This illustrates that there is a chance that increasing policy knowledge in nurses could lead to increased moral distress, rather than solve

the issues that resulted in negative patient outcomes. Further research into this may reveal that simply understanding policy is not always associated with positive patient outcomes.

Limitations

Overall, these sources highlight some of the effects that lack of knowledge can have on hospice and palliative patient care. However, there are limitations to this review that require mentioning. Some of the quantitative studies included had small sample sizes. For example, Kavalieratos et al. had a sample size of 20, Willmott et al. had a sample size of 25, Bradshaw et al. had a sample size of 25, and Cole et al. had a sample size of 362. Alongside limitations that the individual authors mention in their articles, there is also a limitation concerning the relatively small literature sample that was pulled for this review. While this review is helpful in advancing the understanding of how the level of knowledge concerning policies in hospice and palliative care nurses affects patient care, further research should be conducted that examines these effects in further detail, as this review did not result in one clear answer. More research should also be done to investigate possible effective interventions to address lack of knowledge concerning pain administration at the end of life, reporting hesitancy, nonadherence to legislation and policy, and moral distress.

Conclusion

The results of this literature review illustrate that the level of policy knowledge a nurse has can have both positive and negative patient consequences. For example, having an understanding of the protections the nurses have when administering medications at the end of life could result in better managed pain and lead to better quality of life. Knowing that they will be protected from retaliation and have an anonymous reporting system in place has the potential to allow nurses to report more errors, leading to the implementation of systems and policies that

may reduce patient harm. Having a solid understanding of policies that govern hospice and palliative care organizations can allow nurses and organizations to adhere to regulations and prevent legal consequences. However, sometimes having policy knowledge may not result in improved patient outcomes. Instead, it may result in adherence to policies that minimize patient services or dishonor a patient's end of life wishes while increasing moral distress.

While education may help fill some of these knowledge gaps, as has been suggested by many authors in this review, it is not guaranteed to result in better patient outcomes. There is a need for more research to help better understand how the level of understanding of policies affects patient care and how to address negative outcomes. Because healthcare policy is continuously changing, it is important to identify how policy understanding affects patients, so that nurses may be better prepared to address negative outcomes that may come with implementations of new policies. Because one nurse can have such a profound impact on many patient lives, nurses should be involved and educated on new policies and legislation that influence the care they can provide.

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