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A Practice Improvement Project to Improve Knowledge and Perceptions of Palliative Care among Patients with Heart Failure and Cancer in the Acute Setting Using Video Enhanced Education

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The document mentioned above has been reviewed and accepted by the student's advisor, on behalf of the advisory committee, and by the Assistant Dean for MSN and DNP Studies, on behalf of the program; we verify that this is the final, approved version of the student's DNP Project including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

Crystal F. Spellman, Student

Dr. Martha Biddle, Advisor

Final DNP Project Report

A Practice Improvement Project to Improve Knowledge and Perceptions of Palliative Care among Patients with Heart Failure and Cancer in the Acute Setting Using Video Enhanced Education

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Fall 2016

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Clinical Mentor: Jennifer Hester DNP, APRN, ACHPN

Dedication

I dedicate this project to my husband Shawn. Your unwavering support is everything. Thank you especially for all the home cooked meals. They have made people jealous in lunchrooms all over Kentucky. It is also dedicated to Marietta and Perriee, my sisters and biggest cheerleaders. This accomplishment belongs to the three of you too. Thank you and I love you.

In loving memory of Rosemary Luksic.

I hope I gave back to you even a fraction of what you have given to me.

Acknowledgements

When nursing is done right it becomes a team sport. First, I must thank my committee. To my committee chair Martha Biddle, your support made all the difference for me on this journey. It’s been my honor to be your student. To my faculty advisor Debra Moser, thank you for all of your feedback and support through the various phases of my final project. To my clinical mentor Jennifer Hester, thank you for teaching me about the most sacred procedure in palliative care, communication. To Judi Godsey, thank you for all of your feedback, suggestions and unwavering support. To my preceptors Laura Greene, Laura Mitchell and Sharon Ruhl for sharing everything you know about advanced practice nursing with me and for allowing me to be your shadow.

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Introduction to the DNP Practice Inquiry Project

In 1967 Dame Cicely Saunders opened the first hospice in London pioneering the theories and practice of pain control in the dying patient.[1] Since then, the modern hospice and palliative care movement has flourished worldwide. The delivery of palliative care is achieved through an interdisciplinary approach to treat the physical, psychosocial and spiritual dimensions of patients and families living with a serious illness. Palliative care can occur at any stage in the disease trajectory, from the point of diagnosis up until the end of life. The Clinical Nurse Specialist (CNS) is uniquely prepared to reshape existing paradigms for health care delivery and contribute meaningfully to the expansion of the specialty of hospice and palliative care. This practice inquiry project applies the CNS conceptual model describing the three spheres of influence to the hospice and palliative care practice setting.

The conceptual model for CNS practice describes three spheres of influence: the patient/family, nurses and nursing practice, and organizations/systems. In the 50 years since the development of the specialty, the role of the CNS has evolved to address the changing needs of patients along the healthcare continuum, systems delivery models, educational preparations, and the scientific and theoretical underpinnings of outcomes based nursing practice.[2] National Association of Clinical Nurse Specialists states the CNS prepared at the doctoral level will be equipped with additional skills and competencies to advance healthcare and the nursing profession through the evaluation and translation of evidence based practice, utilization of theories and models from a variety of disciplines, improvement of quality of care and safety, and providing the kind of leadership which fosters the interprofessional communication necessary to make these transformational changes.[3]

The following describes the DNP project I implemented and the synthesis of my program of inquiry to fulfil the DNP degree requirements at the University of Kentucky. The first manuscript focuses on the organizations/systems sphere of influence and is an integrative review of the literature describing current practice and recommended standards for the care of patients with implantable cardioverter defibrillators at the end of life in adults. The second manuscript focuses on nurses, the nursing profession and the patient/family sphere. This manuscript describes the adoption of an evidence-based bowel protocol for standing orders in a home hospice environment utilizing the chronic care model as a framework. The final manuscript focuses on the patient/family sphere and describes a study to assess perceptions of palliative care among patients with serious illness in the acute setting utilizing a video enhanced educational intervention.

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Manuscript One

Knowledge and Perceptions of Implantable Cardioverter Defibrillator Deactivation at the End of Life in Adults: An Integrative Review

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Fall 2016

Abstract

Background: Active implantable cardioverter defibrillators (ICDs) have the potential to decrease quality of life patients with terminal cardiac diagnosis at the end of life. The informed consent process prior to device placement should include both short and long term goals as well as consequences of ICD implantation. Often, these ramifications may not be consistently discussed or understood by patients. The purpose of this paper is to conduct an integrative review of the literature to examine the knowledge, attitudes, and perceptions of ICD deactivation and end of life issues among ICD recipients. **Methods:** PubMed was searched using the key words 1) “implantable cardioverter defibrillator” AND “end of life” AND “adult”. Eligible studies were published within the last five years, written in English, and were specific to patient attitudes, knowledge and perceptions of ICD deactivation at the end of life. **Result:** Patients are likely to have insufficient knowledge regarding ICD deactivation, and a minority of them recall receiving information about deactivation from their healthcare provider prior to implantation. Patients with ICDs are less likely to have advance directives in place. Among those that do, these advance directives rarely address ICDs specifically. **Discussion:** Although the literature suggests rate discussions with their health care providers regarding ICD deactivation as important, they continue to demonstrate unrealistic expectations regarding the life prolonging potential of ICDs when considering decision making at end of life. **Conclusion:** The rigorous nature of ICD monitoring provides many opportunities to increase the amount of patients with advanced directives and is consistent with expert recommendations by both the Heart Rhythm Society and the European Heart Rhythm Society.

Key words: implantable cardioverter-defibrillator, end of life care, palliative care

Knowledge and Perceptions of Implantable Cardioverter Defibrillator Deactivation at the End of Life in Adults: An Integrative Review

Implantable cardioverter defibrillator therapy (ICD) is indicated for primary and secondary prevention of sudden cardiac death with measures of left ventricular ejection fraction used to guide appropriateness of therapy. [1] For patients at risk of sudden cardiac death due to ventricular arrhythmias, ICDs can monitor heart rhythm and provide pacing or defibrillation as needed. [2] The American Heart Association [3] estimates that approximately 10,000 individuals are implanted with an ICD each month. Despite these interventions, patients who avoid sudden cardiac death will likely succumb to progressive worsening of underlying heart failure [4] or the development of other progressive life-limiting illnesses. In 2010, approximately one in nine death certificates (about 279,098 deaths) mentioned heart failure. Of these, about 57,757 were directly attributable to heart failure. [5]

Patients have unrealistic expectations of the ICD's ability to prevent cardiac related deaths, particularly those with a diagnosis of heart failure. [6] Extension of ICD therapy into the end of life can have significant negative psychosocial and physical consequences for patients, leading to diminished quality of death. [7,8] The progressive nature of terminal illnesses can increase the likelihood of arrhythmia inducing conditions such as pain, electrolyte abnormalities, hypoxia, sepsis, and worsening heart failure leading to an increased frequency of ICD shocks. [9] Episodes of shock can cause significant physical pain as well as psychological distress for the recipient. [9] A survey of 900 hospice programs in the United States revealed that 97% had admitted at least one patient with an ICD in the preceding year, with 58% of those reporting a patient had received a shock during that time. [10] Device deactivation occurs late in the disease course and is often prompted by acute hospitalizations with a majority of patients having their

ICD deactivated in the last week of life. [11] There are legitimate concerns regarding the economic consequences of prolonged aggressive therapies. The AHA reports that the total direct and indirect costs of cardiovascular disease and stroke in the United States exceed $503 billion, making these disease groups the number one driver of healthcare costs among any other diagnostic group. [12]

Purpose

The Institute of Medicine [13] report "Crossing the Quality Chasm: A New System for the 21st Century" mandates models of care which are patient-centered to achieve optimum quality outcomes. According to this report, patient-centeredness occurs when providers collaborate with patients to design plans of care which are in line with their needs, desires and level of understanding. Consensus statements by the European Heart Rhythm Society [9] and the Heart Rhythm Society [14] affirm that ICD deactivation is both ethically and legally permissible at the end of life. These statements also reiterate the IOM mandate of patient-centered care delivery, recommending that ongoing discussion regarding any cardiovascular implantable electronic devices should begin prior to initiation of these therapies.

The existing literature suggests that provider practice and attitudes regarding end of life issues for patients receiving ICD therapy may be mismatched. Notably, this phenomena has been investigated during the informed consent process among electrophysiologists. [15,16] When asked, physician providers have acknowledged the importance of discussing end of life issues with patients[15,17,18]; however, examinations of medical records do not reflect this intention. [16] To effectively translate the Heart Rhythm Society and European Heart Rhythm Society recommendations into practice both sides of the patient-provider transaction must be understood in order to identify opportunities with the highest likelihood of success. The aim of this integrative review is to synthesize the literature describing the knowledge, attitudes, and perceptions of ICD deactivation and end of life issues among ICD recipients.

Methods

In February 2014 PubMed was searched using the key words 1) “implantable cardioverter defibrillator” AND “end of life” AND “adult” and 2) “implantable cardioverter defibrillator” AND “end of life” AND “deactivation.” From these searches 133 articles were retrieved. After first-stage screening of titles and abstracts 25 of these articles contained all of the search qualifiers and were published within the last five years, and written in English. Next, second-stage screening was performed by reviewing the full text of the remaining articles. Excluded articles included four studies of provider attitudes and practice regarding ICDs at end of life, five case studies or expert recommendations and seven studies not specific to patient knowledge or attitudes regarding ICD deactivation. Nine remaining articles were included in the final review examining end of life issues in adult patients with ICDs (Figure 1.)

Results

Seven of the studies selected for data extraction utilized retrospective cross-sectional correlational designs and two of the selected studies utilized qualitative methodologies (Table 1). The two qualitative studies reviewed both involved patient interviews with a particular focus on what patients recall of their pre-implantation conversations with their physicians regarding end of life decision making or device deactivation. The retrospective cohort studies were able to gather more specific data regarding quantifiable knowledge or attitudes pertaining to ICDs. Data extraction from all of the selected studies revealed three phenomena of interest. First, a snapshot emerged of patients’ current attitudes about end of life decision making specific to their ICDs.

Second, a substantial amount of data regarding patient knowledge of their expectations, general knowledge and ethical concerns emerged. Finally, data arose concerning a mismatch in patient-provider communication.

Current Attitudes

In the qualitative studies reviewed, patients described an awareness of the uncertainty their diagnoses held for the future. Additionally they were able to describe some of their fears surrounding the progression of their illness, [19] and reported a desire for quality of life over quantity. [20] Patients tended towards optimism, focusing on the present and placing great confidence in the ICD's ability to prevent sudden cardiac death, without giving much consideration to the potential for death due to other causes such as progressive comorbid illness or the development of other life-limiting illness such as cancer.

Among the remaining seven studies, between 45.9% [21] and 86% [22] of patients reported that they had not previously considered ICD deactivation at end of life. A telephone survey conducted by Kirkpatrick and colleagues [22] found that among the minority of patients who had considered this, 82% of them had not discussed their concerns with a healthcare provider. The authors also reported that among the cohort of 278 patients who were interviewed in the Kirkpatrick study, 62 (22%) believed the ICD should remain activated in the event of a do not resuscitate order, 90 (32%) believed it should remain activated if the patient enters hospice, and 54 (20%) were uncertain. [22]

Herman and colleagues [21] examined how patients' prior experiences with ICD shocks may affect their attitudes towards deactivation at end of life. In a sample of 112 participants from an outpatient setting, 31 had received a shock after implantation of their ICD. The participants in this group was correlated with an increased likelihood of hospitalization compared to those who had not received prior shocks (1.21 vs 0.79 hospitalizations, $p<0.05$). Participants with prior shock experiences indicated this had an adverse effect on their psychological status. This group also felt they were insufficiently informed about the ICD compared to those with no prior shock experience ($r=-0.368$, $p<0.05$). Cohabitation also seemed to play a role in patient attitudes regarding their ICD. Patients who lived alone were more likely to report their willingness to deactivate their device at end of life compared to those who did not live alone ($r = -0.21$, $p =0.025$). [21]

An alternate study conducted by Raphael and colleagues [23] examined the relationship between patients' prior experiences with ICD shocks and their preferences for device deactivation or end of life discussions with their healthcare provider. Among a group of 54 individuals from an outpatient clinic in Boston, 25% of patients with prior shock were more likely to consider ICD deactivation compared with only 3% of patients who had no prior shock experience ($p = 0.01$). Of the 29 participants who had not received prior shocks, 24% did not want to discuss end of life or deactivation with their healthcare providers. No differences were found in New York Heart Association class, ejection fraction or time since initiation of ICD between groups of patients who would consider deactivation and those who would not. In the event of an ICD shock patients may be forced to confront a new reality with regards to their health and well-being. The authors note that the incidence of an ICD shock may prompt a period of opportunity for healthcare providers to revisit discussions about ICD therapy goals and the possibility of device deactivation in the future.

Patient Knowledge

Patients may have unrealistic expectations of ICDs with predominantly positive attitudes noted towards ICD battery replacement and place great faith in the ability of ICDs to extend life. [19] In the largest study reviewed examining patient knowledge of ICDs, Stromberg and colleagues [24] analyzed written surveys from 3,067 ICD recipients from the Swedish ICD and Pacemaker Registry. The authors found 29% of the sample had insufficient knowledge regarding their ICDs. Within the group, men were more likely to have sufficient knowledge than women (72%, 65%; $p<0.001$) and those less than 65 years old were more likely than those 65 or older to have sufficient knowledge (84%, 65%; $p<0.001$). The authors also found that sufficient knowledge was more likely if the following topics were previously discussed with a physician: battery replacement (n = 1,250; 76% vs 68%; $p<0.001$); deactivation (n=420; 76% vs 71%; $p<0.001$); and illness trajectory (n=1,080; 78% vs 67%; $p<0.001$). [24]

These findings are reinforced by two smaller studies. The Pedersen group [25] noted that 31% of their sample of 294 Dutch patients did not know ICD deactivation was possible. Lower rates were found by Raphael and colleagues, [23] who noted only 3% of their sample (n = 54) could remember being informed of the potential for ICD deactivation at the time of consent. Although 85% of this sample could remember discussing benefits of ICD therapy at the time of informed consent, less than half were able to recall discussing risks or side effects.

Misinformation regarding the ethics of device activation was explored in two studies. In the large national cohort study conducted by Stromberg and colleagues [24] the authors noted 28% (n=796) of respondents believed deactivation to be the same as euthanasia. Those in this category were more likely to be older (68±11 vs 65±12; $p<0.001$), female (31% vs 26%;

p<0.001), with lower education (42% ≤9 years vs 58% education >9 years; p<0.001), low quality of life scores (0.793 vs 0.828; p<0.001), and also had symptoms of depression (36% vs 26%; p<0.001) and anxiety (33% vs 25%: p<0.001). The study conducted by Kirkpatrick and colleagues [22] noted 26% (n=71) considered deactivation synonymous with physician assisted suicide, and 8% (n=23) as unsure. The authors did note a downward trend in these rates over the data collection period between 2009 and 2010 which may have been attributable to spikes in media attention towards palliative and end-of-life issues in response to U.S. health care reform.

Patient-Provider Communication

As alluded to earlier in this review, relatively few patients report having spoken to their physicians about ICD management at end of life. Among a sample of 278 participants, the Kirkpatrick group [22] found that 71 (26%) had a living will, seven (3%) had a healthcare power of attorney and 62 (22%) had both. Kirkpatrick and colleagues [22] also reported that having an advanced directive was significantly associated with age; they reported those with advanced directives had a mean age 65 years compared to a mean age of 57 years among those without advanced directives (p<0.0001). No other characteristics were associated with those who had advanced directives versus those who did not. Most striking is that among this same group only three (2%) participants had an advanced directive which specifically addressed their ICD. Most (n = 267, 96%) had never discussed ICD deactivation at the end of life with a physician. [22]] Herman and colleagues [21] noted similar trends in their sample of 112 participants with 45.9% (n=50) reporting that they had not thought about ICD deactivation at the end of life and only 7.3% (n=8) reporting prior discussions with their physician regarding ICD management at end of life.

Only one study examined demographic characteristics of patients with advanced directives. These patients tended to be older at the time of implantation (69 years vs 60, $p<0.001$), white (97% vs 90, $p<0.02$), and living local to a large center in Minnesota (14% vs 5%, $p = 0.004$). [26] With regards to primary diagnosis, patients with an advanced directive in place were likely to have renal insufficiency (40% vs 26%, $p = 0.005$), COPD (32% vs 45%, $p<0.02$), cancer (36% vs 54%, $p=0.02$) and dementia (4% vs 1%, $p=0.03$) than patients who did not have an advanced directive in place. Even in instances where patients had an existing advanced directive, this did not consistently increase likelihood of deactivation. Of 44 patients who died during this study period, only two patients' advanced directives specifically mentioned ICD management. Additionally, ICD deactivation occurred for only seven patients (16%) at the end of life. This finding suggests that a clear understanding of patient goals and preferences with respect to the management of their ICDs at the end of life is not occurring between patients and their healthcare providers.

General knowledge of advanced directives was addressed in a study conducted by Habal, and colleagues. [27] In their sample of 41 participants from an ambulatory setting in Ontario 31 (76%) did not know what advanced directives were. Of 19 patients with an ICD, only two (11%) reported discussing ICD deactivation with a physician. After patients were educated on the natural course of heart failure, nine (47%) stated they would like deactivation of defibrillator if their condition became worse, five (26%) would not want it deactivated, three (16%) were unsure, and two (11%) did not answer.

Patient preferences for the timing and methods of end of life discussions were examined in two studies. Eighty four percent of a sample population of patients with ICDs surveyed by the Pedersen group [25] believed providers should inform them of the possibility for deactivation, and

62% of these expressed a preference to be informed orally and in writing. Roughly half (49%) of these patients also reported beliefs that end of life discussions should occur before ICD therapy. The Rapheal group [23]observed a similar finding in a sample population of 54 patients with ICDs, with 54% of these individuals expressing a preference for end of life discussions prior to device implantation. In contrast the Kirkpatrick group [22] reported patient preferences for advanced directive discussions at ICD follow up visits (n = 95, 34%) and end of life (n = 110, 40%) versus at the time of device implantation (n = 44, 16%).

Several other factors have been reported which reflect patient preferences for provider communication regarding provider discussions about end of life decision making specific to ICD management. The Pedersen group [25] observed patient preferences for these conversations when life expectancy is decreased (55%), before battery replacement (17%), and during the dying process (26%). Patients responded they preferred these conversations initiated by their electrophysiologists (n = 83, 31%), cardiologists (n = 126, 45%) or primary care physicians (n = 39, 14%). [22] Providers may be reluctant to initiate discussions with patients about ICD management at the end of life, fearing these conversations may contribute to patient distress. However, the Pedersen group (2013) [25] found that the majority of their participants believed discussions would not increase anxiety in themselves (82%) or their families (68%) and that their wish for worthy death at end of life was independently associated with favorable attitude toward deactivation (or 2.14, 95% CI 1.49 to 3.06; $p<0.0001$).

Conclusion

The studies reviewed offer a more global insight into the knowledge, attitudes and desires of patients with ICDs with regards to end of life decision making. It is likely that patients have insufficient knowledge regarding these issues. For patients receiving ICDs, informed consent as well as end of life planning should be considered an ongoing process beginning at the initiation of therapy and continuing through the disease process. Myths regarding the ethics of end of life decision making coupled with unrealistic expectations of these devices to prevent all causes of death persist. Patients without full understanding of these issues may be robbed of the opportunity to make informed choices in line with their values or ideas of life quality or a “good” death.

Although the potential for recall bias is high within several of these retrospective studies which utilize participant interviews, the results do speak to the larger issues of informed consent prior to initiation of therapy, and the frequency with which patients are encouraged to make their desires for end of life through advanced directives, particularly directives which address management of ICDs as applicable. The generalizability of the studies reviewed is one limitation. Several studies in this review had relatively low sample sizes and did not routinely include patients who were at the end of life. Additionally the largest sample of ICD recipients studied was from Sweden [24], which may limit applicability to populations in other parts of the world.

The Heart Rhythm Society [14] and the European Heart Rhythm Society [9] recommend evidence based interventions promote advanced directive discussions including ICD specific directives as standard practice. One quality improvement initiative implanted in a university-affiliated non-for-profit hospice was able to increase the proportion of hospice patients who died with a deactivated device by 27% through the implementation of ICD specific policies and procedures, by making device and manufacturer information more readily accessible, making deactivation magnets universally available, creating an ICD specific care plan, and improving clinician and new-hire education. [28] Although this intervention shows promise for improving quality of death, time can vary significantly between ICD implementation and end of life. The consistent follow up and monitoring of all patients with ICDs during the treatment period [1] presents numerous opportunities to provide adequate information to patients regarding these issues and this course of action is recommended by both the Heart Rhythm Society [14] and the European Heart Rhythm Society. [9] Patient-provider communication and clinical interventions can be enhanced in order to provide patients ample time to make informed decisions regarding their devices and therapy at the end of life.

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Table 1

Summary of Included Studies

Author(s) (Year), Level of Evidence	**Design/Method**	**Purpose**	**Sample/Setting**	**Variables of Interest**	**Findings**	**Significance**
Fluur et al (2013), level of evidence VI	Grounded theory Interview	Patient perspectives on end of life decisions at time decision for ICD intervention.	30 participants from two ICD referral centers in Ontario. (24 accepted ICD; 6 declined ICD).	Quality versus quantity of life. Preferred mode of death. Technical realities of ICD.	Participant focus on avoidance of sudden cardiac death; the potential for death due to other causes not considered by most participants.	End of life issues may not be discussed fully prior to ICD intervention.
Strachan et al (2011), level of evidence VI	Phenomenological Interview	ICD recipients experiences with ICD, battery replacement and end of life issues.	37 patients with ICDs for ≥6 months and not in palliative stage of terminal illness from 5 Swedish hospitals.	Being a part of an uncertain illness trajectory. Standing at a crossroads. Progressing from one phase to another.	Predominant positive attitudes towards ICD replacement; unrealistic attitudes regarding ICD to extend life. Minority of participants said they would make end of life decisions in advance of need or physical decline; few had advanced directives in place addressing the ICD.	Patients may have a poor understanding of disease trajectory. Need exists to discuss end of life issues and promote ICD specific advanced directives with patients who have ICDs.
Stromberg et al (In press) level of evidence IV	Cross-sectional correlational Written survey	Describe knowledge of ICD therapy at end of life among ICD recipients; explore patient-related factors associated with poor insufficient ICD at end of life knowledge.	3,067 ICD recipients recruited from the Swedish ICD and Pacemaker Registry	Knowledge in relation to end of life issues Symptoms of anxiety and depression Quality of life Demographic and clinical variables	29% with insufficient knowledge. Men more likely to have sufficient knowledge than women (72%, 65%; $p<0.001$) Age <65 years more likely than age ≥65 years to have sufficient knowledge (84%, 65%; $p<0.001$). Sufficient knowledge more likely if previously discussed	Large cross sectional study in a national cohort. Population subsets at highest risk include women, older patients, less educated, or with symptoms of anxiety/depression.

					with physician battery replacement (n = 1,250; 76% vs 68%; p<0.001); deactivation (n=420; 76% vs 71%; p<0.001); illness trajectory (n=1,080; 78% vs 67%; p<0.001). 28% (n=796) who believe deactivation is the same as euthanasia were more likely to be older (68±11 vs 65±12; p<0.001), female (31% vs 26%; p<0.001), lower education (42% ≤9 years vs 58% education >9 years; p<0.001); low quality of life score (0.793 vs 0.828; p<0.001), with symptoms of depression (36% vs 26%; p<0.001) and anxiety (33% vs 25%: p<0.001)	
Herman et al (2013), level of evidence IV	Cross-sectional correlational Written survey	Understand patient opinions, attitudes, wishes and understanding of ICDs at end of life.	112 participants with ICDs from an outpatient clinic in the Czech Republic.	Opinions, attitudes, wishes and understanding of ICDs at end of life (13 item questionnaire) Number of prior shocks. Diagnosis of depression. Indication for ICD. Settings of ICD and length of therapy.	45.9% (n=50) had not thought about ICD deactivation at end of life; 7.3% (n=8) had discussed ICD at end of life with their physician. No difference in questions between those with biventricular or non-biventricular devices. No significant difference between patients with ICD for primary or secondary prevention. 28% (n=31) patients had received a shock and were more likely to be hospitalized (1.21	40.1% indicated a desire to be better informed, however only 7.3% of participants reported discussing ICD at end of life with their providers. 25.7% indicated a refusal to discuss deactivation at end of life. Highlights the importance of shared decision making with regards to information

					vs 0.79 hospitalizations, p<0.05). Of these, 8 (7.3%) had received inappropriate shock. Patients who “felt safer” were less likely to consider deactivation (r=-.245, p<0.05); felt sufficiently informed (r=0.2444, p<0.05); and had discusses deactivation (r=0.3, p<0.05). Shocked patients indicated adverse psychological consequences, felt they were insufficiently informed (r=-0.368, p<0.05). Patients who live alone more likely to deactivate at end of life (r= -0.21, p =0.025). Those who considered deactivation indicated they would make the decision without help (r=0.238, p<0.05) .	sharing. However patients may be more receptive to these discussions if better informed.
Pedersen et al (2013), level of evidence IV	Cross-sectional correlational Written survey	Examine patient knowledge and wishes for ICD at end of life information. Examine prevalence and correlations of positive attitudes towards deactivation at end of life.	294 patients identified from a medical center in the Netherlands. Three groups: de novo implanted, moderate experience and considerable experience.	Attitudes towards deactivation. Knowledge about deactivation. Demographic and clinical characteristics. Anxiety, depression and type-D personality.	31% did not know ICD deactivation was possible. 95% of participants believed ICD patients should be informed of the possibility of deactivation. 62% believed patients should be informed orally and in writing. Participants believed discussions should occur before ICD therapy (49%), when life	Trends for response for or against deactivation were seen with anxiety. Most patients do not anticipate increased anxiety in themselves related to end of life discussions. Many patients may be unaware that ICDs can be

					expectancy is decreased (55%), before battery replacement (17%), and during dying process (26%). Participants believed discussions would not increase anxiety in themselves (82%) or their families (68%). 246 participants (84%) could make a choice for or against deactivation. Patients less likely to choose included recent ICD (21%), moderate experience (16%) than those with considerable experience (10%) (n.s.). Of the 246, 195 favored deactivation. Wish for high quality of death independently associated with favorable attitude toward deactivation (or 2.14, 95% CI 1.49 to 3.06; p<0.0001).	deactivated at end of life.
Kirkpatrick et al (2012), level of evidence IV	Cross-sectional correlational Telephone survey	Not stated	278 patients with ICDs extracted from a cardiovascular implantable electronic device clinic in Pennsylvania.	Number of patients with ICDs have advanced directives that explicitly address the ICD Patient preferences for ICD handling particularly at end of life and in a hospice setting.	103 (38%) of participants had been shocked (mean number of shocks 4.69); 80 (30%) were being followed by a palliative care physician; 56 (20%) had a cancer diagnosis. 71 (26%) had a living will; 7 (3%) had a healthcare power of attorney; 62 (22%) had both. Having an advanced directive was significantly associated with age (mean age 65 vs 57 years). No other associated	Patients desire discussions regarding end of life decision making and may prefer this information from their cardiologists or electrophysiologists.

				Belief that deactivation is the equivalent of physician assisted suicide. Perspectives on advanced directives for ICD. Physician preference for ICD handling.	characteristics were noted. Only 3 (2%) participants had an advanced directive which specifically addressed their ICD. Most (n = 267, 96%) had never discussed ICD at end of life with physician. Most (n = 238, 86%) had not considered ICD in the event of serious illness. Of those who had, 30 (82%) had never discussed with a medical practitioner. 11% (n = 28) stated would keep ICD on at end of life; 110 (42%) were unsure. 26% (n=71) considered deactivation synonymous with physician assisted suicide, 8% (n=23) were unsure (trended downward in 2010). 264 (95%) believed patients should have the chance to complete an ICD specific advanced directive. Most believed advanced directives should be initiated at follow up visit (n = 95, 34%), at end of life (n = 110, 40%) versus at implantation (n = 44, 16%)	
Tajouri, et al (2012), level of evidence IV	Cross-sectional correlational Retrospective chart review	Determine advanced directive prevalence among ICD recipients as well as the	420 patients who had ICD implanted at the Mayo Clinic in Minnesota.	Patients with advanced directive	Patients with advanced directives were older at time of implantation (69 years vs 60, $p<0.001$), white (97% vs 90, $p<0.02$), and lived in Olmstead	Patients often include general information regarding “life-sustaining”

		frequency with which advanced directives address ICD management at end of life.	Group 1: ICD present (n = 127) Group 2: ICD absent (n = 293)	Characteristics of the advanced directive	County (local), Minnesota (14% vs 5%, p = 0.004). Patient with advanced directive likely to have renal insufficiency (40% vs 26%, p = 0.005), COPD (p<0.02), cancer (p=0.02) and dementia (p=0.03). Differences between patients with ICD for primary or secondary prevention with and without advanced directive were not significant. Of 44 patients who died, ICD was deactivated in 7 (16%). advanced directive did not increase likelihood of deactivation. Of the patients with an advanced directive the majority were completed 12 months prior to implantation (83, 65%), the fewest completed after implantation (10, 8%) Only 2 advanced directives mentioned ICD or instructions for end of life.	treatments in their advanced directive. Further education is need to clarify exact goals of care.
Habal, et al (2011), level of evidence IV	Cross-sectional correlational Prospective, semi-structured interviews	Determine HF patients' awareness, understanding and utilization of advanced directives.	41 participants from an ambulatory heart function clinic in Ontario.	Demographics. Awareness of advanced directives	31 (76%) did not know what advanced directives were. Of 19 patients with an ICD, only 2 (11%) reported discussing ICD deactivation with a physician.	Patients require additional opportunities for education in order to make the most informed decisions.

				Knowledge of resuscitation options Current resuscitation preference	After patients educated on natural course of HF 9 (47%) stated they would like deactivation of defibrillator if their condition became worse; 5 (26%) would not want it deactivated; 3 (16%) were unsure; 2 (11%) did not answer.	
Raphael et al (2011), level of evidence IV	Cross-sectional correlational Semi-structured interview	Describe patient understanding of consent for ICD intervention. Determine attitudes towards future deactivation.	54 patients from a tertiary heart failure referral center in Boston. Group 1: (N=29) ICD but no shocks Group 2: (N=25) ICD for 6 months and at least one shock	Recollection of consent Timing of deactivation discussions Appropriate situations for device deactivation Option of variable switch-off device.	85% recall discussing benefits at time of consent, less than half recall discussing risks or side effects. 3% remember being informed the ICD could be deactivated at time of consent, 38% report becoming aware of potential for ICD deactivation later. 24% of never shocked group did not want to discuss end of life. 84% believed ICD deactivation should be discussed with provider; 52% believed these conversation should occur before ICD intervention.	Discussions regarding deactivation should take place prior to initiation of ICD therapy, and reviewed after any shock therapy.

Levels of evidence: Melnyk and Fineout-Overholt[29]:
I. Evidence obtained from a systematic review or meta-analysis of all relevant randomized controlled trials
II. Evidence obtained from at least one randomized controlled trial
III. Evidence obtained from well-designed controlled trials without randomization
IV. Evidence obtained from well-designed case control and cohort studies
V. Evidence obtained from systematic reviews of descriptive and qualitative studies
VI. Evidence from a single descriptive or qualitative study
VII. Evidence from opinion of authorities and/or reports of expert committees

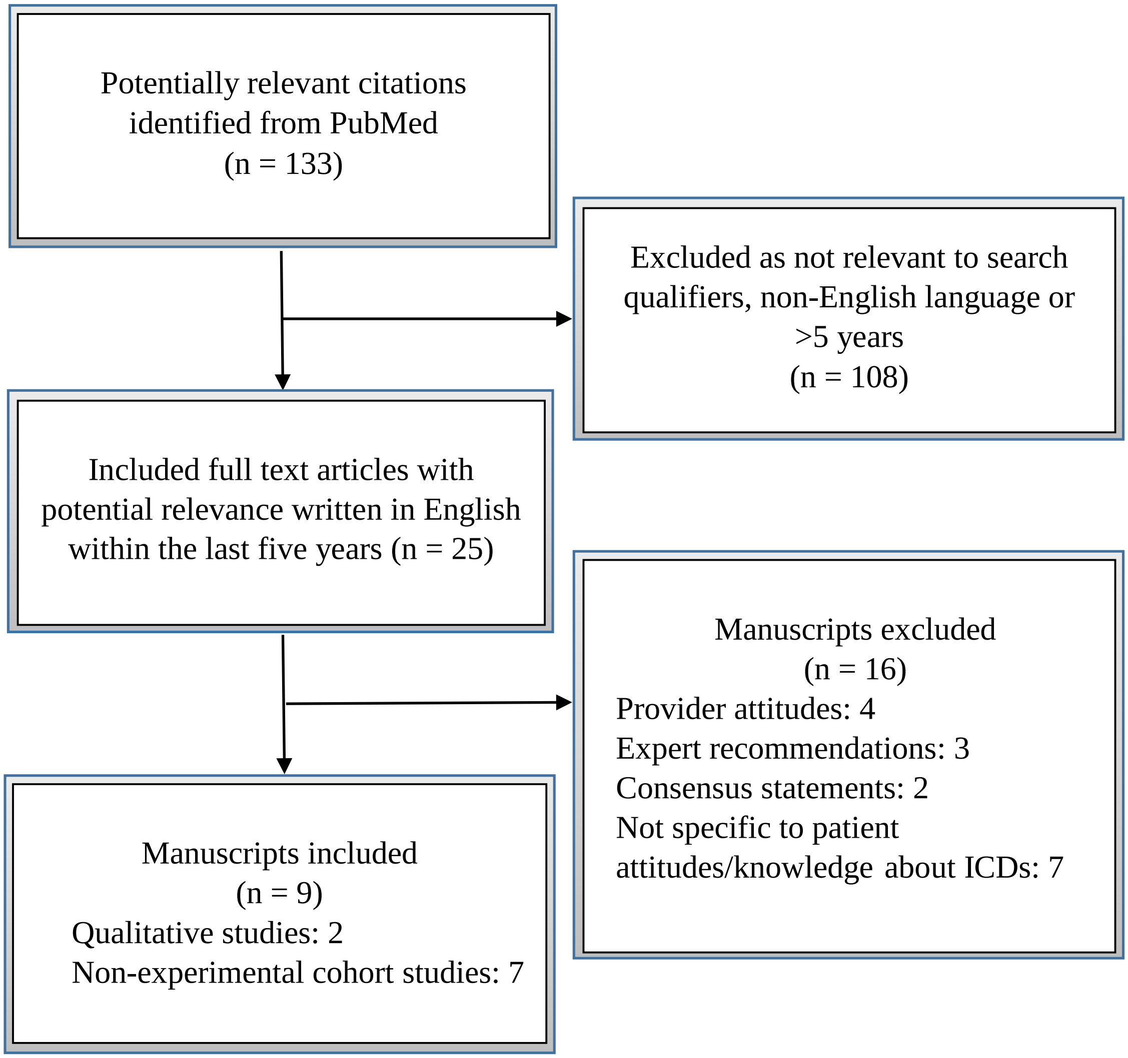

Figure 1. Study selection scheme

Manuscript Two

Adoption of an Evidence-Based Bowel Protocol for Standing Orders in a Home Hospice Program Utilizing Patient Experience Data as an Evaluative Component

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Abstract

Background: Prevalence of constipation in home hospice patients has been estimated between 22% and 90%, with higher prevalence indicated when patients are self-reporting symptoms. The Centers for Medicare and Medicaid Services are adjusting reimbursements for hospice services based on the subjective experiences of symptom management among patients and their caregivers. The purpose of this paper is to describe the process of a nurse led practice improvement project to implement an evidence-based standing order set for constipation management in a home hospice setting utilizing patient experience data as an evaluative component. **Methods:** The steps of the Iowa Model for Evidence Based Practice Change were utilized for this practice implementation project. Hospice CAHPS Survey data was monitored as a proxy for intervention effectiveness. **Results:** Quarterly tracking and analysis of patient experience data regarding constipation management provided ongoing and reflexive feedback which was able to shape targeted interventions to improve outcomes. **Discussion:** As hospice nurses begin to appraise and adapt the evidence for constipation management, such data can prove useful in monitoring impact and adjusting practice accordingly to optimize outcomes. **Conclusion:** The roles of nursing in shared governance committees, quality assurance and performance improvement are complementary in the implementation of evidence based practice changes and monitoring effectiveness.

Key words: Quality assurance; performance improvement; CAHPS; constipation.

Adoption of an Evidence-Based Bowel Protocol for Standing Orders in a Home Hospice Utilizing Patient Experience Data as an Evaluative Component

Home hospice organizations are instrumental in promoting patient centered care to patients and families at the end of life. A fundamental aspect of quality hospice care is support of patients and families through expert pain and symptom management. One study estimated 92% of home hospice patients received an opioid during the last two months of their life [1]. The role of opioids in the development of constipation is well established and development of constipation is further complicated by functional decline and disease progression. The reported prevalence of constipation in palliative care populations varies with estimates between 22% and 90%[2-4]. One study of patients admitted to specialized Palliative Care units in Sweden found the prevalence of constipation varied depending on the definition used. A 7% prevalence of constipation was observed when using a frequency-based definition versus a prevalence of 43% when constipation was patient-reported.

The subjective experiences of patients and families is fast becoming a key component of health care reimbursement. The Centers for Medicare and Medicaid (CMS) has led this shift with their Value Based Purchasing Program, or “pay for performance” which utilizes weighted scores for process and patient experience to determine reimbursement for hospitals. Similarly CMS has responded to the mandate set forth from the Affordable Care Act of 2010 requiring hospice programs submit quality data via the Hospice Quality Reporting Program[5]. The Hospice Quality Reporting Program supports the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey to gauge the experience and satisfaction of hospice patients through their identified informal caregivers[6]. There are several eligibility requirements for the hospice CAHPS survey. The decedent must be at least 18 years of age and their death must have occurred at least 48 hours following their last hospice admission date. There must be a primary caregiver on record in which to mail the survey and the caregiver has not previously declined to be contacted. The caregiver of record must also reside within the U. S. or a U. S. Territory. All surveys are administered by a third party CAHPS Hospice Survey vendor approved by the Centers for Medicare and Medicaid and contracted directly from the participating hospice. Caregivers for decedents of all payer sources and across all settings of hospice care (inpatient, home, assisted living, nursing home) are eligible for participation[7].

Conflicting and inconclusive evidence for the treatment of constipation among patients at or nearing the end of life complicates best practice adoption and implementation. In any setting, constipation is best treated through a patient centered approach which takes patients' expectations into consideration as well as their perceptions of symptom burden[8]. Shared governance councils are ideal vehicles for advancement of evidence based practice changes within institutions [9]. Improvements in professional engagement have been demonstrated by evaluations of shared governance structures revealing that nurses feel their voices are strengthened, that they are able to take ownership of the practice environment and that interprofessional collaborations are promoted to solve complex clinical problems [10]. The purpose of this paper is to describe the process of a nurse led practice improvement project to implement an evidence-based standing order set for constipation management in a home hospice setting utilizing patient experience data as an evaluative component.

Methods

The Iowa Model of Evidence-Based Practice

The Iowa Model of Evidence-Based Practice as described by Titler and colleagues (2001) provides the framework for identification of a relevant topic for clinical inquiry, team formation, appraisal and synthesis of the relevant best evidence, application of changes, evaluation and dissemination. Step one involves identifying a problem-focused or knowledge-focused trigger where an evidence based practice change may be needed. Second, the determination must be made if the identified problem is indeed an organizational priority. Third, a team should be assembled to develop the evidence based practice change. Fourth, the team must develop the research question and then collect any relevant evidence in the literature. Fifth, the team must critique and synthesize the research for use in practice. Sixth, after the team determines the amount and quality of the available evidence is adequate an implementation plan is developed. Seventh, once the practice is determined adaptable, the team may decide to make further refinements or, if the change is appropriate for adoption it may be instituted. Eighth, the practice change is then monitored through observation and analysis of structure, process and outcome data. Finally, the results are disseminated [11,12].

Population and Setting

This evidence based practice improvement project occurred at a community-based, hospital affiliated non-profit hospice organization in northern Kentucky between October 2015 and October 2016. The program serves patients in seven counties and cares for them in their private residences, assisted living communities and long term care facilities. The program maintains an average daily census of approximately 160 patients. Registered nurses responsible for triage of phone calls after regular business hours began to notice a trend of increased patient and family complaints of constipation with fecal impaction. Although standing orders for management of constipation were available for registered nurses to initiate when clinically indicated, they had not been updated to reflect changes in practice knowledge. These problem focused triggers initiated the evidence-based practice change cycle, prompting a review of current practices, processes and protocols.

Data Collection and Analysis

At the next point in the Iowa Model, a decision must be made to determine if the problem is an organizational priority. During monthly meetings of the of the home hospice unit based design council the group worked collaboratively to determine this. In order to tease out possible sources of the problem, a data tracking form was shared with after-hours hospice staff in order to monitor patient and family reported incidence of impaction. Several communications were sent to all nursing staff asking for participation in gathering this data. Thirteen incidents of impaction were noted in an eight-week period. The most frequently cited comment reported was patient medication non-adherence. During the same time period, the quality assurance and performance improvement nurses began pilot implementation of quality measure data collection for the Hospice CAHPS Survey. The unit based design council and the quality assurance and performance improvement nurses identified two constipation related measures on the Hospice CAHPS Survey to use as external benchmarks for measuring the success of planned practice changes. The following questions were used: 1) While your family member was in hospice care, did your family member ever have trouble with constipation; and 2) How often did your family member get the help he or she needed for trouble with constipation. Responses were measured on a four point Likert-type scale (“never”, “sometimes”, “usually”, “always”) with “always” identified as the target response.

Process Implementation

The unit based design team working with the quality assurance performance improvement nurses became the core team for the practice change. The team sought out and received the support of the nurse managers, hospice medical director and the collaborating hospice pharmacist. All members of the team made themselves available to review and approve any proposed changes. The unit based design team was then able to develop the research question in order to collect and appraise the relevant evidence (Table 1).

The next step of the Iowa Model describes the development of an implementation plan. After the evidence was synthesized and critiqued by the team, the standing order set for bowel management was evaluated for consistency with current practice recommendations, evidence, cost effectiveness and population need (Figure 1). Several changes were made to the order set including the increasing the prn dose range for Senokot-S to reflect a maximum therapeutic dose of one to four tabs twice daily; the addition of a Bisacodyl 10mg rectal suppository daily as needed; and the addition of time-based parameters for the initiation of rectal interventions. Recognizing the importance of continued staff education to coincide with the implementation of the new standing order set, further refinements were made to the intervention. First, hospice-specific, evidence-based clinical reference material in the form of a computer based learning module was made available to all nursing staff. Second, clinical information systems were reviewed for their utility and ease of use. Specifically, the team reviewed the current electronic medical record flowsheet for gastrointestinal assessment and collaborated to evaluate the accessibility of the standing order set in the patient chart.

Results

Outcomes evaluation of the practice change includes monitoring and analysis of structure and process data including environment, staff, cost and impact on the patient and family. The key outcome measure determined by the workgroup became quarterly monitoring of the CAHPS Hospice Survey. In the first quarter of Hospice CAHPS reporting this hospice met the national benchmark for total number of “always” responses to the questions “Patient received help for constipation.” These results revealed additional opportunities for further improvement, including improving perception of constipation management for hospice patients in nursing homes. To follow up, the team began discussions with the unit team leader, a key member of the team dedicated to education and practice improvement of the electronic medical record. The team began to develop methods to extract additional evaluative reporting data include incidence of rectal interventions and documentation of primary caregiver bowel management teaching. Finally, dissemination of information including instruction and rationale for bowel regimen and patient experience data tracking changes was shared during unit based design council meetings, nursing team meetings. Additionally, the quality assurance and performance improvement nurses maintained public bulletin boards reporting patient experience data.

Discussion

Bowel regimens are necessary as constipation can produce significant physical symptoms for the terminally ill patient including pain, nausea and vomiting, rectal tears and bleeding, bloating or abdominal distention, a sense of fullness and a sense of urgency [13]. When untreated, constipation can lead to increasingly severe complications including anorexia, dehydration, abdominal pain, urinary retention or in severe cases, total bowel obstruction. Psychological distress related to constipation and its symptoms can lead to poor quality of life for both the patient and caregivers manifesting as anxiety, depression or agitation [3,14]. Additionally, patients may assign meaning to their worsening constipation and identify it as a sign of worsening disease or health status [14]. Planned interventions must take into consideration involvement of the patient and caregiver to promote a patient centered approach which aligns all treatments with patient goals, preferences and values. Many causes of constipation may not be easily reversible in the hospice patient as the progressive worsening of a life limiting disease often leads to a compounding effect of causative factors [15].

Successful symptom management is a core service of any hospice program. The importance of successful management of symptoms, particularly constipation is illustrated in the patient experience data collection currently being implemented by the Centers for Medicare and Medicaid Services. Although public reporting of the Hospice CAHPS Survey is not estimated to begin until 2018, failure to comply with CMS submission guidelines for quality data results in a 2 point penalty for reimbursements, in effect creating a “pay for reporting” reimbursement system[5]. Hospices which are early adopters of this quality reporting program have the opportunity to strengthen programs which support the best possible patient outcomes while simultaneously maximizing reimbursement potential for their programs.

Conclusion

Clavelle and colleagues (2016) have re-conceptualized shared governance as *professional governance* and define it as “the accountability, professional obligation, collateral relationships and decision-making of a professional, foundational to autonomous practice and achievement of exemplary empirical outcomes.” (p. 310). In this example shared governance is a model supportive of professional nursing practice which operates interdependently of management. [16]. Shared governance structures empower nurses to take ownership of practice patterns, improve nursing care quality, maintain professional competence and act as stewards of nursing knowledge through its creation and dissemination [12,16].

Evidence based nursing care lies at the intersection of best evidence, expert opinion and the stated values, goals and preferences of patients and families. Interventions aimed at management of constipation by the hospice and palliative care nurse must continuously be evaluated through the lens of patient and caregiver perceptions of care to achieve patient centered care. Continued innovation is needed in the realms of research and performance improvement to arrive at improved interventions and prevention strategies for the management of constipation in populations nearing or at the end of life. Patient experience surveys create an essential foundation to an emerging paradigm in healthcare where quality care with the patient at the nucleus is incentivized. Hospice programs with robust frontline leadership teams in collaboration with quality assurance and performance improvement teams will be best prepared for the transition to increased transparency via public reporting programs. Perhaps more importantly hospice programs with this framework in place will increase their organizational agility by quickly identifying related patterns in patient and family reported experiences and clinical outcomes and responding accordingly.

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Table 1

Summary of Evidence

Author(s), Year	Design/Model	Purpose	Sample/Setting	Variables of Interest	Significance
Abernathy et al. (2003)[17]	Review	Summary of palliative management of GI symptoms in advanced cancer patients.	NA	Nausea/Vomiting Constipation Diarrhea	Constipation rates for terminally ill cancer patients between 50-87%
Andrews & Morgan (2013)[18]	Expert recommendation	Improved assessment and complex symptom management can enhance patient self-management and sense of control.	NA	Assessment; contributing factors; psychological impact; physiological impact; treatment options; lifestyle changes	NA
Candy et al. (2015)[15]	Meta-analysis of seven RCTs involving 616 participants	To evaluate the effectiveness of laxatives versus methylnatrexone for prophylaxis or treatment of constipation	616 patients with advanced cancer or other chronic life limiting illnesses.	Laxation, methylnaltrexone, lactulose, senna, codanthramer, misrakasneham, magnesium hydroxide with liquid paraffin.	No clear superior treatment for constipation management can be established.
Clark & Currow (2013)[4]	Systematic review of 20 articles examining treatment of constipation in a hospice/palliative care setting.	To systematically examine the definition and primary outcome measures used to study constipation among hospice/palliative care populations.	20 articles examining treatment of constipation in a hospice/palliative care setting.	Primary outcomes varied and included: laxation, bowel function, defecation-free intervals of 72 hours, time to laxation, number and types of laxatives, constipation severity, average number of bowel actions in the preceding three weeks.	There is an unmet need for a validated tool that can be used to evaluate constipation consistently in the literature.
Hawley & Byeon (2008)[19]	Nonrandomized, non-blinded sequential cohort study	To compare the effectiveness of sennosides	60 Canadian patients hospitalized >5 days with a cancer diagnosis: 30 docusate plus sennosides protocol	Sennosides only protocol produced significantly more BM than sennosides with docusate protocol ($p<0.05$). Sennosides only group admitted for symptom control and supportive care had more BMs >50% of days compared to sennosides plus docusate (62.5% vs 32%). More patients receiving sennosides	Sennosides only were more effective at inducing laxation. No difference in incidence of bowel cramps was noted between groups.

			(control) versus 30 sennosides only protocol (intervention)	plus doscusate received supplement of lactulose, suppository or enema (57% vs 40%); cramping reported equally in both groups; diarrhea more frequent in sennosides only group (27% vs 13%)	
Librach et al. (2010)[20]	Expert recommendation	To define best practices in constipation management for patients with advanced progressive illness.	NA	Best practices include assessment, physical examination, non-pharmacological interventions (toileting, mobility, increasing oral intake if appropriate) and pharmacological interventions.	While its role is limited to treatment of opioid induced constipation, methylnaltrexone is recommended to improve sleep.
Larkin et al. (2008)[21]	Expert recommendation	To define best practices in constipation management for patients enrolled in palliative care.	NA	Treatment of constipation focused on addressing the underlying cause. The use of a stimulant laxative combined with a softening agent is recommended.	Data describing safety and efficacy of laxatives in a palliative care population are limited.
Tarumi, Wilson, Szafran & Spooner (2013)[22]	RCT	To assess efficacy of docusate in hospice patients.	74 patients from three Canadian inpatient hospice units. (35 docusate group, 39 placebo group).	No significant difference between the sennosides and docusate group vs sennosides alone.	Addition of docusate to bowel regimen should carefully consider continued assessment findings, overall medication burden and patient preference.
Thomas et al. (2008)[23]	RCT	To assess safety and efficacy of subcutaneous methylnaltrexone in palliative care patients with opioid induced constipation.			

OLD ORDERS	NEW ORDERS
• Increase fluids and exercise as tolerated • Senokot-S tablets oral 1-2 tablets BID or Miralax 17gm in 8oz fluid daily PRN • Administer Fleets, Soap Suds or Milk and Molasses enema PRN	• Increase fluids and exercise as tolerated • Senokot-S tablets 1-4 tablets BID OR Miralax 17grams in 8oz fluid daily PRN • Bisacodyl 10mg rectal suppository daily prn (no BM x3 days **or PRN**) • Administer fleets, soap suds or mineral oil or milk and molasses enema PRN (no BM >3 days **or PRN**)

Figure 1. Comparison between old and new standing orders

Manuscript Three

A Practice Improvement Project to Improve Knowledge and Perceptions of Palliative Care among Patients with Heart Failure and Cancer in the Acute Setting Using Video Enhanced Education

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Abstract

Background: Clear communication of the purpose and benefits of palliative care can reduce barriers to acceptance of such services for patients and families. The purpose of this practice improvement project was to assess and improve knowledge and perceptions of palliative care among patients with a diagnosis of heart failure and cancer in the acute setting using a video enhanced education intervention. **Methods**: This practice improvement project took place at a 555 bed teaching hospital. 18 patients referred to an inpatient palliative care consult service in the acute care setting with a diagnosis of either heart failure or cancer participated. **Result:** Paired sample t-tests were conducted to examine the effectiveness of the intervention in patients' scores assessing level of palliative care awareness (Table 2). There was a significant positive difference in the scores for level of palliative care awareness before (M = 2.56, SD = 1.25) and after (M = 3.72, SD = 1.179) a five-minute video describing palliative care; t(17) = 3.82 p = .001. **Discussion:** Video interventions delivered at the point of care in the acute setting may be an effective tool for improving knowledge and perceptions of palliative care among patient with diagnoses of heart failure or cancer. **Conclusion:** The benefits of video education may be enhanced when delivered with the addition of face to face interaction by a member of the healthcare team versus a video self-administered by the patient. Further evaluation is needed.

Key Words: palliative care; patient education; video enhanced education

A Practice Improvement Project to Improve Knowledge and Perceptions of Palliative Care among Patients with Heart Failure and Cancer in the Acute Setting Using Video Enhanced Education

The World Health Organization[1] defines palliative care as "…an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems - physical, psychosocial, and spiritual." Palliative care is a medical specialty that can be accessed for any individual living with a serious illness and is appropriate for persons at any stage of a serious illness at any age. Members of the palliative care team work alongside members of the patient's primary care team to provide an extra layer of support and assist in alleviating the symptoms, pain and stress of a serious illness. Members of the palliative care team can help clarify patients' and families' goals of care and assist in the alignment of prescribed medical treatments with these desires. Models for palliative care delivery exist in both inpatient and outpatient settings.[2]

Palliative care continues to be a growing medical specialty due to multiple factors. In particular, the impact on national health and overall disease burden among aging baby boomers nation-wide is estimated to result in the rapid growth of persons aged 65 and older between 2010 and 2050. By the year 2050 the projected number of Americans aged 65 and older is 88.5 million – effectively doubling the current size of this population.[3] As the population continues to age the incidence of persons living with a serious illness is estimated to increase correspondingly. According to the Centers for Disease Control and Prevention the top three causes of death in the United States in 2013 were heart disease (611,105), cancer (585,881) and chronic lower respiratory diseases (149,205)[4]. Currently an estimated 80% of older adults are living with a chronic condition and an estimated 50% are living with at least two chronic conditions further contributing to their influx into the acute and ambulatory settings.[4]

At the end of a serious illness trajectory the medical and nursing care that is delivered becomes increasingly complex. Hospice care, which currently requires a physician certification that an individual has six months or less to live, is a philosophy of care delivery which falls under the umbrella of palliative care. Unfortunately "just in time" hospice utilization has been ineffective in reducing resource utilization, with duration of hospice enrollment averaging 3 days and often preceded by multiple transitions in care during the last months of life.[5] One proposed solution to the escalation of resource utilization at the end of a serious illness trajectory is to increase the frequency of advanced care planning conversations with patients and families prior to condition deterioration. These discussions are facilitated by expert palliative care clinicians can elicit patient preferences for treatment at the end of life so that the care patients receive is in line with their values, beliefs and informed decisions. Effective advanced care planning conversations decrease resource utilization and aggregate health care costs [6-9] and have demonstrated positive effects on caregiver-reported quality of death.[8] In addition to enhancing patient centered care through expertly managed advanced care planning, palliative care has been associated with reduced patient suffering, improved symptom recognition, improved pain management, improved quality of life and improved survival outcomes for oncology patients receiving palliative care concurrent with curative treatments.[10-14]

Problem

A 2011 study commissioned by the Center to Advance Palliative Care created a snapshot of public awareness, attitudes and perceptions of palliative care[15] to provide a framework to improve communication regarding the benefits and future direction of this specialty with consumers and policymakers. Data were collected from a national survey of 800 adults age 18 or older to assess current palliative care knowledge. When asked, “How knowledgeable, if at all, are you about palliative care?” the overwhelming majority of respondents reported they were “not at all knowledgeable” about palliative care. After information was provided to patients regarding palliative care using clear, understandable language, an increase in individuals’ willingness to incorporate palliative care into their medical care was observed. Among persons who reported no prior knowledge about palliative care and were given the opportunity to gain an increased understanding about it, 92% reported they would be likely to utilize palliative care services if they or their families were confronted with a serious illness. Additionally, 92% of these individuals believed that they should have access to palliative care in the hospital setting.[15]

During transitions in care, particularly as individuals move between outpatient to inpatient settings, patient education becomes critical and should be a continuous intervention.[16] It is likely that inpatients admitted for treatment related to their serious illness are unaware that palliative care services are available to them, and that this issue is further complicated by the fact that healthcare providers may use the terms “palliative care” and “end of life care” or “hospice” interchangeably. Educational interventions targeted at improving knowledge and understanding of palliative care should include standardized messages which have been tested in order to best dispel myths and eliminate the confusion which exists for patients as they learn to differentiate between hospice and palliative care.[15]

Review of the Literature

Currently, multiple national and specialty-specific guidelines recommend early integration of palliative care for patients with serious illness. For patients with advanced heart failure the American Heart Association recommends involvement of the palliative care team prior to a patient reaching refractory end stage heart failure.[17] For patients with advanced metastatic cancer diagnoses, the early integration of palliative care is supported by the National Comprehensive Cancer Network which cites uncontrolled symptoms, moderate to severe diagnosis or treatment related distress, serious comorbidity, a life expectancy of one year or less, patient or family concerns regarding any aspect of the disease course or related decision-making or the request of patients or family members as indications for a palliative care referral.[18] Similarly the American Society of Clinical Oncology issued a provisional clinical opinion that palliative care should be considered for any patient with metastatic cancer and/or a high symptom burden after a phase III randomized controlled trial found increased survival benefit, improvement in symptoms, improved quality of life, increased patient satisfaction and reduced caregiver burden when palliative care was combined with standard anti-cancer therapy.[14,19]

Confusion, myths and fear persist among the public and health care providers alike regarding how to best define palliative care. A review of the literature utilizing “palliative care” as a search term returns a greater number of studies written about end of life or hospice issues than papers examining the role of palliative care in a role supportive to active or curative treatments.[20] The Institute of Medicine’s 2014 report, “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life” identified key recommendations for improving quality and patient-centered outcomes for individuals approaching the end of life including the delivery of person-centered, family-oriented care and improved clinician-patient communication.[21] Communicating the key messages and goals of palliative care effectively reduce barriers to patient participation in palliative care programs and is an essential step to improving outcomes.

Patients are able to make informed decisions reflecting their values, goals and beliefs when they have accurate information about palliative care. One qualitative study explored public awareness and perceptions of palliative care.[22] When asked, patients in the study expressed the importance of dispelling myths surrounding palliative care and that public education through TV advertisements, posters and leaflets, and inviting cancer survivors to act as “ambassadors” to educate others were valued educational strategies.[22] Patients and families desire accurate information which enables them to make educated decisions regarding their planned medical care. This finding further supports the findings of the Center to Advance Palliative Care public opinion study cited earlier.[15]

To date, the seminal Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)[23] is the largest study examining outcomes related to enhanced communication between seriously ill patients and health care providers. No significant improvements were noted in key outcome variables such as incidence and timing of written DNR orders, physician knowledge of resuscitation preferences, ICU length of stay, and incidence of mechanical ventilation or reduced hospital resource utilization as a result of a patient-physician communication intervention. Interventions which address patient-physician communication alone may not be enough to impact patient-centered outcomes for the seriously ill.

With the exception of the Center to Advance Palliative Care commissioned survey, there are few contemporary studies exploring educational interventions to enhance palliative care knowledge and awareness for patients. Additionally, a few recent studies have explored opportunities during an acute hospitalization to provide education, which distinguishes the difference between palliative care and hospice or end of life services. A video enhanced educational intervention provides a unique opportunity to clarify the principles of palliative care for patients in the acute care setting and can be delivered by any member of the interdisciplinary team. The purpose of this practice improvement project was to improve knowledge and perceptions of palliative care among patients with a diagnosis of heart failure and cancer in the acute setting using a video enhanced education intervention.

Methods

Design, Sample and Setting

The setting for this project was a 555 bed teaching hospital in Cincinnati, Ohio. The palliative care service at this facility is composed of advanced practice nurses, registered nurses, social workers, physicians and chaplains with expertise in palliative care. Consultations are triggered on admission for all patients with a diagnoses of advanced metastatic cancer or advanced (New York Heart Association Class III/IV) heart failure by the attending physician. Activities of the palliative care service include advanced symptom assessment and management, care coordination among multiple specialties, management and support of the spiritual, cultural and emotional aspects of care, advanced care planning and expert communication of patient and family goals of care to the entire healthcare team.

For the purposes of this practice improvement project, the target population was composed of acutely ill inpatients with diagnoses of either advanced hematologic or solid tumor cancer or advanced heart failure referred to the palliative care service. A portion of the accessible population reported prior exposure to palliative care services at this facility from a previous admission. As such, this subset of patients serves as a distinct comparison group with patients with patients having no previous palliative care experience. Patients considered for inclusion were adults 18 years of age or older, English speaking, inpatients referred to the palliative care service with a heart failure or cancer diagnosis, able and willing to provide consent and participate voluntarily and able to respond verbally to the survey questions administered. Permission was obtained from The Christ Hospital Institutional Review Board and the University of Kentucky Institutional Review Board. Decisional capacity was determined by successful completion of a six-item dichotomous (yes/no) screening tool prior to patients providing consent to participate. Data collection occurred between April 1 and June 31, 2016. A convenience sample of 18 patients was identified within the described population who met inclusion criteria for recruitment into this practice improvement project.

Video Enhanced Education

A brief video was created by myself in collaboration with the palliative care team which describes the concept and philosophy of palliative care as well as summarizes the palliative care service available specifically at facility. All media utilized to create the video was obtained with permission under a royalty free license. Stock audio media was provided by TuneLight/Pond5.com and stock video footage was provided by Eldelik, Monkey Business Images, Wavebreakmedia Ltd and Dreamstime.com. Recording of the narrative, editing and production took place at the University of Kentucky Media Depot. The video was reviewed and approved by the interdisciplinary palliative care team. The acute care hospital retains proprietary rights to the video. The video script (Appendix A) was derived from “Brochure Guidelines” by the Center to Advance Palliative Care and incorporates messaging guidance from public opinion research.[15] A video education format was favored for several reasons. Video-enhanced education is a cost effective method of delivering information to inpatient populations. A video can be easily delivered to the bedside on-demand and can be provided by the primary nurse, who may be the first to identify patients who could benefit from palliative care.

Evaluation

Descriptive demographic data collected includes patient age, gender, race, level of education, employment status and marital status. Health related demographic data includes diagnosis (cardiac or oncologic), previous contact or interaction with the palliative care consult team, hospital visit type (planned or acute) and palliative performance scale score. Palliative performance scale scores were extracted from the patient electronic medical record.

Level of awareness of palliative care was assessed utilizing a five-point Likert-type scale whereby patients were asked to report “not any knowledge”, “only a little knowledge”, “unsure”, “some knowledge” or “a lot of knowledge”. All patients were then asked to respond to ten additional statements from a survey assessing palliative care knowledge. This survey reflected the messaging recommendations by the Center to Advance Palliative Care utilizing a ten-item, five-point Likert-type survey (“strongly agree”, “disagree”, “unsure”, “agree”, “strongly agree”). The survey asked patients to rank the following items regarding inpatient palliative care: Improves quality of life for patients; improves quality of life for families; provides compassionate care; can help me manage my pain; can help me manage symptoms other than pain such as shortness of breath or nausea; can be given along my regular (life-prolonging) treatments for my condition; is made up of a team of doctors, nurses, social workers, chaplains and pharmacists; can assist me with any spiritual or emotional concerns I have; provides an extra layer of support for me and my family; will communicate with my primary doctor about my condition. The survey and level of palliative care knowledge patient reported assessment were administered at baseline and immediately after the video intervention to evaluate affective learning.

Procedure

Patients identified as eligible for inclusion were approached by the principle investigator. The study's purpose and protocol were explained in detail to the patient. Informed consent was obtained and documented by the principle investigator. Upon giving their informed consent, patients were given a content evaluation survey to assess their prior knowledge of palliative care. Patients were then asked to view the educational video describing palliative care and the content evaluation survey was repeated. All surveys were administered verbally by the principal investigator. Data were managed using REDCap (Research Electronic Data Capture) electronic data capture tools hosted at The University of Kentucky College of Nursing.[24] REDCap is a secure, web-based application designed to support data capture for research studies, providing 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources[24].

Data Management and Analysis

Descriptive statistics were used to summarize the demographic and clinical characteristics of the patients. Paired t-tests were used to assess changes in palliative care knowledge between baseline and immediate post intervention scores. Change scores were calculated as the difference between the post-intervention and baseline scores for palliative care knowledge. All data analysis was conducted using SPSS version 20 and an alpha level of 0.5 was used throughout.

Results

Among 18 patients 10 (55.6%) were female and 14 (77.8%) were Caucasian. More patients were admitted with a primary diagnosis of cancer (n=12; 66.7%) than heart failure (n=6;

33.3%). A greater number of patients in the sample reported their admission as the first contact with the palliative care team (n=12; 66.7%) than those reporting contact during a prior admission (n=6; 33.3%) (Table 1).

Paired sample t-tests were conducted to examine the effectiveness of the intervention in patients' scores assessing level of palliative care awareness (Table 2). There was a positive difference in the scores for level of palliative care awareness pre (M = 2.56, SD = 1.25) and post (M = 3.72, SD = 1.179) video intervention; t(17) = 3.82 p = .001. Positive differences were also noted for the following survey items before and after the video education intervention respectively: “Palliative care improves quality of life for patients” (M = 3.78, SD = .73; M = 4.22, SD = .73; t(17) = 3.69 p = .002); “Palliative care improves quality of life for families” (M = 3.89, SD = .76; M = 4.22, SD = .65; t(17) = 2.92 p = .010); “Palliative care can help me manage symptoms other than pain such as shortness of breath or nausea” (M = 3.50, SD = .79; M = 4.11, SD = .90; t(17) = 3.72 p = .002); “Palliative care can be given along with my regular (life-prolonging) treatments for my condition” (M = 3.89, SD = .68; M = 4.39, SD = .50; t(17) = 3.43 p = .003); “Palliative provides an extra layer of support for me and my family” (M = 3.83, SD = .86; M = 4.28, SD = .75; t(17) = 3.06 p = .007); “The palliative care will communicate with my primary doctor about my condition” (M = 4.00, SD = .69; M = 4.50, SD = .51; t(17) = 4.12 p = .001); Overall, there was a statistically significant increase in total palliative care knowledge scores pre video intervention (M=41.56, SD=6.64) and post video intervention (M=46.61, SD= 6.25); t(17) = 4.83, p < .0005. (Table 2). The mean increase in total scores was 5.06 with a 95% confidence interval ranging from 7.26 to 2.85. The eta squared statistic (0.58) indicating a large effect size.

Discussion

Prior research supports our findings of the efficacy of video based interventions on increasing knowledge related to disease. Frosch and colleagues compared a group of men aged ≥50 years of age who received education from a video about the risks and benefits of PSA screening and found a video-based decision aid (n=112) was significantly more effective than information presented via the internet (n=114) (t (221) = 4.07, $P < .001$), [25] reflecting results similar to those found by these authors. This could be due to two reasons. First, the video interventions in the Frosch group's study and these authors' intervention have the advantage of being available at the point of care and were initiated in the health care setting where patients were likely to be present to their current health concerns. Second, Frosch and colleagues suggest that patients may prefer health information from reputable and trustworthy sources such as directly from the healthcare provider in the acute care setting. A video delivered to palliative care patients during an inpatient hospital stay may influence patient perceptions of the trustworthiness of educational intervention however further evaluation is needed.

In another study conducted by Moonaghi and colleagues, attitudes related to diet and fluid intake among 75 hemodialysis patients were assessed at four data points after face-to-face and video educational interventions.[26] The authors found no significant differences and equal efficacy between face to face and video methods of education at baseline, two and four weeks post intervention (face to face: respectively; $p < .001$, $p < .001$, $p <.001$; video: $p < .001$, $p < .001$, $p = .001$). It is important to note that when these authors delivered the palliative care video education, encounter times with patients averaged about an hour. Often, the act of collecting demographic data (asking patients' if their admission was acute versus planned for example) elicited historical narratives including details about recent treatments, complications, frustrations and hopes. It is possible that receiving the video intervention at the bedside with the opportunity to ask questions and have a member of the healthcare team bear witness to the patient's experience is preferable to the delivery of a video that a patient self-administers or views independently. Further research regarding the benefits of interventions which combine elements of face to face and video enhanced teaching in palliative care populations is needed.

Generalizability of the results obtained from this practice improvement project to a larger population is limited by the small sample size. In addition, a larger sample could have illuminated differences in change scores associated with demographic elements of the sample. However, by including patients with both heart failure and cancer this sample is representative of those patients in the acute care setting who are most likely to utilize palliative care services. The video and the survey used to assess palliative care knowledge were developed to ensure consistency with tested language recommended by the Center to Advance Palliative Care. Although consensus recommendations exist for inpatient palliative care programs, variation among hospitals and regions exists between programs with regards to program maturity, staffing and clarity of mission and vision. While the video includes material that is specific to the palliative care program available at this facility, it does contain content based on national recommendations and is reflective of the best evidence available for practice change in this population.

Measures for health related quality of life and patients' perceived involvement in care were intended to be part of the final analysis, however these were incorrectly administered thus invalidating the data. Inclusion of these measures could have provided further insight into possible associations between any changes in palliative care knowledge and perceived involvement in care or quality of life, particularly if these evaluations could have occurred in low up period of patients were discharged. Conducting research with palliative care populations poses unique challenges. Patients eligible for palliative care consultation in a hospital setting are by definition higher acuity with the potential for rapid changes in functional status and a limited prognosis due to their advanced illness, limiting the feasibility of long-term follow-up.

Conclusion

The video as proposed is designed to be available to all inpatient nursing staff as an educational aid for palliative care appropriate patients within the project setting. The video will be made available in the patient education television channel, SkyLite. Utilizing this technology allows the electronic medical record to be updated when the video is shown to a patient to document the patient has received this education. This practice improvement project is significant because it addresses common barriers in palliative care communication to patients who are hospitalized in an acute care setting. Scripted communication fulfils the goals of palliative care education to patients, families, and non-specialty members of the healthcare team while simultaneously strengthening the messages presented by specialist team members. Effective communication is an essential clinical tool in the palliative care professional’s arsenal. As the palliative care specialty continues to define mission and vision and evolve its scientific basis for practice a consistent presentation and clear message is needed to provide a clear picture of what palliative care is, and what it is not to enable patients to make the difficult decisions needed to receive the medical care they desire through the serious illness continuum.

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Table 1

Demographic Characteristics of Participant Sample

Variables	Frequency (n=18)	Percentage
Age		
< 65	11	61.1%
≥ 65	7	38.9%
Gender		
Female	10	55.6%
Male	8	44.4%
Race		
Black or African American	4	22.2%
White or Caucasian	14	77.8%
Education		
Some high school	3	16.7%
Some college	12	66.7%
Graduate degree	3	16.7%
Employment status		
Employed	2	11.1%
Unemployed	0	-
Retired	8	44.4%
Disabled	8	44.4%
Relationship status		
Married/partnered	12	66.7%
Single/living alone	6	33.3%
Primary diagnosis		
Cancer	12	66.7%
Heart Failure	6	33.3%
Hospital visit type		
Planned	5	27.8%
Acute	13	72.2%
Previous palliative care contact		
Yes	6	33.3%
No	12	66.7%
Self –reported health status		
Excellent	0	-
Very Good	3	16.7%
Good	6	33.3%
Fair	6	33.3%
Poor	3	16.7%

Table 2

Repeated Measures Data from Pre and Post Video Intervention Survey Scores

	Mean (Pre and Post Video)	Std. Deviation (Pre and Post Video)	t*	p (< .05)
Level of palliative care awareness	2.56 3.72	1.25 1.18	3.823	.001
Quality patient care	3.78 4.22	.73 .73	3.688	.002
Quality for families	3.89 4.22	.76 .65	2.915	.010
Compassion	4.22 4.39	.73 .78	.825	.421
Pain management	3.72 4.17	.83 .86	1.917	.072
Symptoms managed	3.50 4.11	.79 .90	3.716	.002
Regular treatment	3.89 4.39	.68 .50	3.431	.003
Team	4.11 4.39	.68 .61	1.567	.135
Spiritual	4.00 4.22	.84 1.00	1.719	.104
Support	3.83 4.28	.86 .75	3.063	.007
Communication	4.00 4.50	.69 .51	4.123	.001
Total Score	41.56 46.61	6.64 6.25	4.832	<.0005

Conclusion

Professor of psychiatry and medicine at Harvard Medical School Susan Block states, "Our main procedure in palliative care is difficult communication[1] Indeed communicating difficult information, whether related to the impacts of a life limiting illness, or urging nurses and colleagues from other health care disciplines that changes in practice can achieve better outcomes. The palliative care CNS is uniquely poised to impact change and improve patient care outcomes in the palliative care specialty. The findings of this practice inquiry project illuminate the potential impact of the DNP prepared CNS working to advance the palliative care specialty through translation and implementation of practice changes within all three CNS spheres of influence by acknowledging the interrelatedness of each aspect of the healthcare system.

The integrative review summarizing patient attitudes and knowledge about Implantable Cardioverter Defibrillator deactivation creates a path for practice change within the organizations/systems sphere of influence. Through critical appraisal and synthesis of the current barriers to patient knowledge, the CNS can initiate the interdisciplinary dialogue needed to create sustainable changes in practice that facilitate optimal palliative care delivery at the primary level among generalist members of the healthcare team, as well at the secondary level, among specialist palliative care providers. The second manuscript focusing on the nurse and nursing sphere of influence describes the integration of best evidence into practice to optimize bowel management for hospice patients. This is accomplished through the application of the Iowa Model for evidence based practice integration and monitored utilizing national benchmarks to evaluate effectiveness and to continue to identify new areas for improvement. Finally, the implementation of a video enhanced education intervention illustrates the impact of the CNS at the patient/family sphere of influence. Through the translation of existing research and expert recommendations, a bedside intervention for seriously ill patients creates the opportunity to improve understanding of key palliative care concepts, thereby creating access to care by reducing barriers created by misinformation and fear. The three spheres of influence model of CNS practice acknowledges the interrelatedness of each aspect of the healthcare system. This ultimately impacts current practices at the micro and macro levels and will be essential in driving new and meaningful changes in a fragmented healthcare system.

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Appendix A

Palliative Care Script

If you are seriously ill, you should know that The Christ Hospital has a special program to help you during your hospitalization. The Christ Hospital's Palliative Care Service provides comprehensive and compassionate care focused on relief of suffering and improvement of quality of life for patients and families coping with serious illness while they are in the hospital. Palliative care is specialized medical care for people with serious illnesses. This type of care focuses on relieving the symptoms, pain and stresses of a serious illness—whatever the diagnosis.

The goal of palliative care is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses and other specialists working in partnership with a patient, their medical specialists and their family to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.

Who is on the palliative care team?
The team is made up of physicians, nurses, chaplains, social workers and pharmacists experienced in palliative care. They will work alongside the patient's other doctors and healthcare providers.

What happens during a palliative care consultation?
A doctor and/or nurse who specializes in palliative care will review the patient's records and speak with the patient's other doctors. Members of the team will meet with the patient and/or his or her loved ones to assess patient and family needs. When appropriate, they will arrange a family care conference to discuss the patient's medical issues, options and goals of care. The team will document findings in the medical record and make recommendations for treatment when necessary.

What types of treatment can be provided?
The palliative care team will provide care based on the unique needs of each patient. Patient and family involvement is encouraged to foster a better understanding of the illness and goals of care.

- The palliative care team can address symptoms such as pain, trouble sleeping, shortness of breath, nausea, weakness and other conditions causing discomfort.
- The team can coordinate care when several specialists are treating varying aspects of the patient's illness.
- The team can assist with making daily physical activities easier and offer exercise and nutrition planning.
- Specialists in spiritual care and social work can address the spiritual, cultural and emotional aspects of care.
- Team members will support patients and families to ensure their goals of care are clearly understood and aligned with the medical treatments offered, especially if the patient becomes unable to communicate his or her wishes.
- The team will assist patients, their families and the hospital staff to make plans for care upon discharge from the hospital.

Is palliative care just another name for hospice?
Palliative care is often confused with hospice – which is care focused on comfort when life-prolonging treatments are no longer helpful. Palliative care is different. Even patients who are expected to fully recover from a serious illness may benefit from palliative care services, which can be provided alongside full life-prolonging treatments.

How are palliative care consultations requested?
A palliative care consultation requires a doctor's order. If you believe that you or your loved one would benefit from palliative care, you may ask your doctor to request a consultation. You may also receive more information by calling the palliative care team at 513-585-4157.

Palliative care reflects The Christ Hospital's commitment to patient- and family-centered care, which focuses on treating patients and families with dignity and respect, information sharing, participation and collaboration. Through this service, we hope to empower patients and families to make healthcare decisions with peace of mind.

Appendix B

Level of Palliative Care Awareness Survey

1. Please rate your level of awareness of palliative care:

(1) Not any knowledge

(2) Only a little knowledge

(3) Unsure

(4) Some knowledge

(5) A lot of knowledge

Please answer the following questions regarding palliative care:

2. Palliative care improves quality of life for patients

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

3. Palliative care improves quality of life for families

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

4. Palliative care provides compassionate care

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

5. Palliative care can help me manage my pain

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

6. Palliative care can help me manage symptoms other than pain such as shortness of breath or nausea

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

7. Palliative care can be given along my regular (life-prolonging) treatments for my condition

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

8. Palliative care is made up of a team of doctors, nurses, social workers, chaplains and pharmacists

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

9. Palliative care can assist me with any spiritual or emotional concerns I have

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

10. Palliative care provides an extra layer of support for me and my family

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

11. The palliative care team will communicate with my primary doctor about my condition

(1) Strongly disagree

(2) Disagree

(3) Unsure

(4) Agree

(5) Strongly agree

Appendix C

Center to Advance Palliative Care (2011) Key Messages

Key Messages	Definition of Palliative Care
Key messages are essential tools for any kind of communication with your audience. They bridge what your audience already knows with where you are trying to lead them. Your key messages will change depending on the topic or question you're going to address. Most of the time you will want to use no more than three key messages. The top messages below reinforce for the public the goals of palliative care. They address the topic/question "What is palliative care? " • Palliative care helps to provide the best possible quality of life for a patient and their family. • Palliative care helps patients and families manage the pain, symptoms, and stress of serious illness. • Palliative care is a partnership of patient, medical specialists, and family. • Palliative care is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment. • Palliative care provides an extra layer of support for families and patients with serious illness.	The following definition should be used when defining or describing palliative care for consumers: Palliative care is specialized medical care for people with serious illnesses. This type of care is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work with a patient's other doctors to provide an extra layer of support. Palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment.