Timely Transitioning to Hospice: A Needs Assessment with a PACE Program to Improve End of Life Care

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Timely Transitioning to Hospice: A Needs Assessment with a PACE Program to Improve End of Life Care

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# Table of Contents

Abstract ............................................................................................................................................. 4

Introduction ........................................................................................................................................ 5

  Background.................................................................................................................................... 5

  Problem Statement ....................................................................................................................... 7

Organizational “Gap” Analysis of Project Site .................................................................................. 7

Review of the Literature (related to evidence-based practice/s to address the problem) ........... 8

  Evidence Based Practice: Verification of Chosen Option .......................................................... 11

Theoretical Framework/Evidence Based Practice Model ............................................................... 12

Goals, Objectives & Expected Outcomes ...................................................................................... 13

Project Design .................................................................................................................................. 14

  Project Site and Population ......................................................................................................... 15

Implementation Plan/Procedures .................................................................................................... 15

  Outcome Measurement(s) .......................................................................................................... 16

  Data Collection Procedure ....................................................................................................... 17

  Ethical Considerations/Protection of Human Subjects ............................................................. 17

Results ............................................................................................................................................... 18

Discussion ...................................................................................................................................... 21
TRANSITIONING TO HOSPICE WITH A PACE PROGRAM

Setting Facilitators and Barriers .............................................................................. 24

Conclusion .................................................................................................................. 25

References .................................................................................................................. 26

Appendix ..................................................................................................................... 30

Appendix A .................................................................................................................. 30

Appendix B .................................................................................................................. 31

Appendix C .................................................................................................................. 32

Appendix D .................................................................................................................. 34

Appendix E .................................................................................................................. 35

Appendix F .................................................................................................................. 48

Appendix G .................................................................................................................. 49

Appendix H .................................................................................................................. 50

Appendix I .................................................................................................................. 51
Abstract

Background: Hospice care has been proven to improve patient outcomes at the end of life. However, patients frequently die without receiving hospice benefits. The challenge of transitioning patients from care with a life prolonging intent to a comfort focused approach can partly be attributed to poor prognostication or misconceptions about hospice. A Program for All Inclusive Care of Elders (PACE) in Massachusetts identified transitioning to hospice as an area for improvement. Purpose: To perform a needs assessment to gain understanding of the barriers to effective transitions to hospice and to provide education aimed at addressing those barriers. Methods: Subjects included nurses, nutritionists, physical and occupational therapists. These healthcare providers were surveyed to assess facilitators and barriers to hospice transitions. An educational presentation and focus group based on the results was conducted and evaluated using post-surveys. Results: Eleven individuals participated in the needs assessment survey. Lack of communication surrounding end of life care transitions was the most frequently identified barrier to care. The educational intervention focused on communication strategies and the post-survey evaluated participant satisfaction on the topic. Six participants were present for the presentation, 5 completed the post-survey following the intervention and 2 completed the 2-month follow-up. Due to the low response rate for the 2-month follow up it was not clear that there was a change in satisfaction among participants. Conclusion: A needs assessment is valuable in understanding why patients are not receiving adequate hospice services at the end of life. These results can effectively direct interventions that aim to improve care transitions.

Keywords: hospice, palliative care, end of life, transition, needs assessment, and quality improvement
Introduction

The Program of All-Inclusive Care for the Elderly (PACE) provides comprehensive medical and social care to individuals who are 55 years or older, eligible for nursing home care, who can live safely in the community and live in an area that PACE serves (PACE4You, 2018). Under this model an interdisciplinary team (IDT) provides care to patients from the time of enrollment until the time of their death with a goal of helping them remain at home and in the community. At the end of life, specialty therapies are incorporated into the care plan of a PACE patient to their address physical, social, psychological, and spiritual needs (Smith & Reilly, 2017). The Program for All Inclusive Care of Elders treats patients on a continuum of care, including identifying the appropriate time to transition to end of life care and communicating that effectively. This transition can be especially challenging when providers have been so intimately and consistently involved in a patient’s care, however, this care model provides a great opportunity to improve quality of life and relieve suffering. Understanding and addressing the challenges PACE team members encounter during end of life care transitions can make a meaningful impact in optimizing patient outcomes.

Background

In the United States (US), 2,712,630 people died in 2015 (CDC, 2017). Of those deaths, heart disease, cancer, chronic lower respiratory diseases, Alzheimer’s disease, diabetes, and kidney disease are among the top ten causes. These are all considered to be common chronic diseases for which people seek care and are common reasons why patients are enrolled into PACE programs. In 2014 an estimated 1.6-1.7 million patients received end of life care through hospice services and about 47.3% of Medicare recipients who died utilized these services (National Hospice and Palliative Care Organization, 2015).
These statistics on hospice utilization are important because they reflect the volume of patients who do and do not utilize the benefit of hospice when hospice has been shown to improve quality of life and the length of life for those nearing death (Temel et al., 2010). Additionally, hospice has been proven to improve symptom management, reduce hospitalizations, improve patient and family satisfaction with end of life care, and lower costs (Welch, 2008). With such evidence present it is concerning that over half of those who die each year do not access this specialty care.

Of those who do enroll in hospice the average length of stay is about 20 days, but research has shown that there is a far greater benefit for those who are enrolled for more than 30 days (Ford, Nietert, Zapka, Zoller, & Silvestri, 2008). The cause of limited hospice length of stays is multifactorial but transitioning from care with a curative intent to care strictly for symptom management is a prominent cause. This is partially due to patients, their families, and providers feeling like they are “giving up” when they change course to hospice care. Evidence also shows that health care providers ineffectively communicating prognosis and being unable to identify when patients are declining without the chance of recovery are barriers to hospice enrollment. Prognosis is an important factor for health care providers to make a hospice referral, as it needs to be determined that the patient has less than six months to live for coverage of the services (Romo, Wallhagen, & Smith, 2017). Patients are more likely to accept hospice care when they are aware that their prognosis is limited, however research indicates that patients tend to overestimate how long they will live despite poor prognoses. These determinants make the process of hospice referral by a health care provider and acceptance of hospice services by a patient challenging and lead to ineffective transitions to end of life care.
The site for this project identified an area of need surrounding the transition of patients to hospice care. Clinically, PACE leaders feel that they have many patients who die unexpectedly and are unable to utilize hospice care or not use it for long enough to reap the benefits. They also expressed concern with IDT members, such as nurses, nurse practitioners, and doctors, communicating effectively with patients and their families during hospice transition and end of life care. Specifically, they have identified a need for improvement of effective communication for ancillary staff members, such as, patient drivers, home health aides and schedulers. Due to the evidence that has shown that hospice care improves the quality of life for patients and their family members when faced with a terminal illness, this PACE program, requested that a needs assessment be conducted, and an educational intervention offered to address identified needs.

**Problem Statement**

Risk of ineffective or delayed transitions to hospice care among patients enrolled in a PACE program is indicated by the limited number of patients receiving hospice care at the end of life and short length of time receiving that care and results from lack of IDT awareness of patient prognosis and timely transition to hospice care in general.

**Organizational “Gap” Analysis of Project Site**

PACE programs are unique in that they treat patients on a continuum of care, from the time of enrollment to the time of death, with a focus that goes beyond therapeutic interventions. PACE programs take a multi-dimensional approach to care that incorporates an IDT whose members include more than just physicians and nurses. Drivers, social workers, physical therapists, dieticians, schedulers, and front desk staff are all involved with patient care at PACE and impact end of life quality. The current process for altering a patient’s plan of care to include hospice interventions is to determine that they are experiencing a terminal decline and that they
have less than six months left to live. The decision is made with the IDT, the patient, and their family to cease treatment with a curative or life prolonging intent and focus on symptom management and comfort. The IDT has expressed that under this system patients are either not making it to hospice or doing so at a point where they are not able to reap its full benefits.

The PACE program leaders identified end of life care transitions as an area of need and hypothesized that IDT experience, comfort, and skill levels could be influential factors. To begin the task of improving upon this concern it was important to first understand the reality and depth of this problem. Gathering information on whether the staff as whole believes patients are being ineffectively transitioned to end of life care and why they think this is aided the direct the path for addressing the problem.

In addressing this assessment, it was speculated that there were likely several causes of ineffective transitioning of patients to end of life at PACE, but it was difficult to comprehend them all currently due to the lack of existing data. A needs assessment of staff views and understanding of this issue was conducted to inform educational initiatives aimed at improving these processes. Poor prognostication, unsuccessful communication of prognosis and patient goals of care, and desire to maintain hope were presumed to be the causes of ineffective transitioning based on current evidence (Waldrop & Rinfrette, 2009). An educational presentation, based on this assessment, was also created and aimed at addressing these areas with the goal of improving transitioning of patients to end of life care with the PACE program.

**Review of the Literature**

A complete review of available literature was conducted to appraise existing evidence of needs assessment of health care provider staff for quality end of life care. This information was obtained by searching the CINHAL, Pub Med, and American Nurses Association databases. The
search terms utilized for this literature review were *hospice, palliative care, primary care, end of life, transition, needs assessment, staff education, and quality improvement*. Articles were included if they were in the English language, published within the past 10 years, detailed quality improvement and needs assessment analyses on palliative, end of life or hospice care, and had an evidence level of IV-I with a good or high quality based on the Johns Hopkins Nursing Evidence Based Practice Scale (Dang & Dearholt, 2017). Research that included needs assessment for hospice, end of life care, or palliative care were included. Research that explored the relationships between needs assessments and educational interventions were included. Research was included that provided different strategies for needs assessments to better inform the process by which data was then collected for this project. Articles that discussed evidence for educational interventions aimed at end of life care transitions were also included.

Articles were excluded that were not relevant to the topic and of level V evidence with low quality or major flaws. There were many articles that were on the topic of improving strategies for end of life care, but these were excluded if these did not perform a needs assessment in a hospice, palliative or end of life setting. Many articles are available that discuss research on end of life educational interventions, but these were excluded if they did not directly address improving transitioning patients to end of life care.

A search of the Pub Med database revealed 94 results and of those 4 publications met the criteria for review. The CINHAL database revealed 231 results and of those 6 publications met the criteria for review and 2 additional publications were duplicated from the Pub Med search. The American Nurses Association search did not reveal any pertinent publications for this review. There were 134 results but of those only one was relevant to the background of this topic and none fit the criteria for inclusion regarding the appropriate level of evidence. Over all 7
studies were utilized to inform this project and they were all descriptive research studies.

**Needs Assessment for Hospice and Palliative Care**

Needs assessments aimed at understanding staff practices in palliative care, hospice, and end of life care have been performed. Palliative care and hospice/end of life care are not the same, because palliative care can coincide with active treatment whereas hospice commences after treatment has stopped (MedlinePlus, 2018). Both focus on comfort through interventions aimed at symptom management and quality of life. Research has been completed to gather data that would provide understanding to areas of need, address staffing shortages and customize educational initiatives in the field (Coats et al., 2017; Namaslvayam & Barnett, 2016). These studies are cross-sectional descriptive studies that utilize surveys and either one on one interviews or focus groups to collect data. The Likert scale was the most commonly utilized method of surveying. Data included topics of patient and family communication, symptom management, communication for care coordination, views in palliative care and death and dying, and what education staff members felt is most needed. Results revealed that while staff often feel equipped to manage patient’s symptoms, they do not feel qualified to have conversations regarding goals of care and end of life transitions.

**Educational Interventions**

Educational interventions identified by those who will be receiving them are thought to be more effective than those chosen by the educators themselves (Carroll, Weisbrod, O’Connor, & Quill, 2018). For this reason, the needs assessment that includes surveys of the staff to highlight perceived areas of deficiency are helpful. Carroll et al. (2018) created a survey geared toward nonpalliative care specialists to better understand their perspectives on barriers to caring for patients with palliative care needs. The survey was a series of topics related to palliative care
and the participants were asked, on a scale, of their “desire/need to improve” versus their “lack of interest/need.” A different approach to this is to ask open ended questions, as Mitchell, Loew, Millington-Sanders, and Dale have done (2016). Their survey asked questions, such as, “What are the main barriers/enablers you experience to be able to manage patients at the end of life and their families?” Both surveys yielded valid insight on perceived areas for improvement in end of life care.

Research has been performed on educational interventions that utilize information from needs assessments to improve transitions to end of life care. One example of such a research intervention was a simple letter to oncologists informing them that 67% of an expert panel recommended hospice care for 90 days and 27% indicated 45 days was ideal (Von Gunten, 2016). After this letter was distributed the average length of hospice stay for the target population increased from 21 days to 44 days between 2014 and 2016. Beyea, Fischer, Schenck, and Hanson (2013) took a more complex approach to an education initiative and included an in-person education training and in-house staff specializing in end of life care discussions and they similarly found that referrals to hospice went up after the initiative and referrals were happening earlier in the process. They also surveyed staff post intervention and found that the intervention was viewed in a positive manner and that participants felt that their practice would change as a result. Analyzing the efficacy of these interventions can also include surveying staff knowledge of presented topics pre- and post-educational intervention (Cocoran, 2016). Staff members with greater knowledge in end of life care will have greater comfort and a higher likelihood to initiate appropriate transitions.

**Evidence Based Practice: Verification of Chosen Option**
Based on evidence obtained in studies aimed at improving the transition process of patients to hospice care this project took the approach of understanding the IDT perception of need as well as their general knowledge, comfort level and beliefs on the topic. This was accomplished through a survey-based needs assessment for the IDT and based on the results of that an educational intervention was performed to address the areas identified for improvement. The combined approach of identifying perceived needs and then addressing them using evidence-based information optimizes the success of the program aimed to improve quality of timely transition to hospice for patients at the end of life.

**Theoretical Framework/Evidence Based Practice Model**

Lewin’s Change Theory is the primary model on which this project was built. Lewin’s Change Theory was deemed appropriate because it addresses each necessary phase of this project, including, creating problem awareness, providing evidence-based alternatives, and integrating the evidence-based alternatives into the status quo (Lewin, 1951; Wojciechowski, Pearsall, Murphy, & French, 2016). Lewin describes these three phases as Unfreezing, Changing, Refreezing (See Appendix A for an infographic on Lewin’s Change Theory).

Performing a needs assessment to understand what the issues at hand were and then describing the results to the participants is the unfreezing phase. Changing required a customized educational intervention aimed at challenging the status quo and providing evidence for improved practices. Refreezing will take time but will prove that the change was necessary to provide better outcomes for patients. By moving from an area of ineffective transitions to hospice to effective transitions to hospice, staff will understand that the change was necessary and new status quo will be created.
A secondary model, the Lee Geropalliative Caring Model (Lee, 2018) was incorporated as the framework for the educational intervention. The goal of this nursing theory is to provide person-centered care that aims to achieve well-being among frail older people during the last 2 years of life. The model consists of four domains: 1. Aligning Care, which focuses on the patient as a unique individual with values, goals and preferences that should be considered. 2. Keeping safe, which is aimed at preventing harm and promoting healing. 3. Comforting body-mind-spirit, which considers the patient as more than just a body to care for and heal but as a holistic being that needs the mind and spirit tended to for optimal comfort and healing. 4. Facilitating transitions, which helps individuals accept the next phase of their care. This model was ideal for informing the educational intervention because the four domains provide topic specific focus that is relevant to the goal of the intervention. (See Appendix B for an infographic on the Lee Geropalliative Caring Model).

**Goals, Objectives, and Expected Outcomes**

The overarching goal of this project was to improve patient transitions to hospice care within a PACE program. This was accomplished by improving the understanding of IDT needs and perceptions in transitioning patients to hospice care and improving IDT knowledge of how to effectively transition patients to hospice care.

Improving the understanding of IDT needs in transitioning patients to hospice care was accomplished by a survey-based needs assessment. This survey was conducted beginning in September 2018 and ending in mid-October 2018 and the data collected from the responses resulted in improved understanding of overall needs.
The goal of improving IDT knowledge of how to efficiently transition patients to hospice care was accomplished through this educational intervention. It was determined during this project that the most effective way to evaluate the efficacy of this intervention was by measuring subject satisfaction on the specific content covered. The intention was to improve satisfaction by a measurable amount determined by comparing the post intervention surveys immediately following the presentation and 2 months later. If 40% of subjects changed their satisfaction in the direction of dissatisfied to satisfied in each of the 6 questions surveyed than the intervention could be deemed as successful among this group of IDT members.

**Project Design**

This was a quality improvement design project aimed at advancing the process of transitioning patients to hospice along a continuum of care. This project occurred in two main phases.

**Phase One.** The first phase was aimed at increasing the understanding of current beliefs and practices when transitioning patients to hospice. This was accomplished through a needs assessment survey given to all IDT staff members. The survey was based on one that was created by Mitchell, Loew, Millington-Sanders, and Dale (2016). The main survey question was “What are the main barriers/enablers you experience transitioning patients to hospice care.” (See Appendix C for the Needs Assessment Survey)

**Phase Two.** The second phase was the educational intervention that was customized based on frequently occurring answers to the perceived barriers from the survey. This was done on December 14, 2018. The success of the intervention was measured using post-surveys pertaining to the information presented (See Appendix D for Post-surveys). Pre-surveys were not
utilized because the goal of the survey was to assess subject satisfaction with their sites ability to perform in the identified areas of need. As the education intervention simply provided information and did not make any immediate changes pre-surveys would not have provided any useful information for this specific intervention.

**Project Site and Population**

The project site was a health care office in Massachusetts that utilizes the PACE program model. This facility includes an adult day center and medical clinic. The subject population for this project was the IDT that included; nutritionists, occupational/physical therapists, nurses, and an administrative director. This project mainly focused on understanding the perceived barriers to end of life care; the overarching aim was that patients will benefit through more effective transitions to hospice.

**Implementation Plan/Procedures**

The initial step in implementing this project was to become familiar with the project site and participants. This was accomplished during site visits and attending IDT meetings to meet participants and explain the project. There was an introductory presentation at an IDT meeting prior to administering the needs assessment survey to explain the project rationale, timeline, goals of the study, and instructions for completing the surveys. During the IDT meeting participants were asked for their email addresses so that surveys could be sent to them for completion. It was explained that this was a voluntary survey and staff were not required to participate.

The surveys were sent by email and participants had four weeks to complete them. Once the survey results were received the responses were then recorded in an Excel spreadsheet for
ease of access and quantification. After all surveys were completed and answers categorized the results were evaluated to determine the most common areas of need identified by IDT members.

Once the common themes of staff needs were known an educational intervention was created based on evidence based best practices and presented to the IDT. The presentation was a PowerPoint presentation and divided into two sections including: review of the needs assessment survey results and review of literature on end of life care transitions addressing areas of identified needs (See Appendix E for the Power Point Presentation Slides). This was followed by a focus group to brainstorm ideas of the next steps the group would like to take to directly address these areas of need. Presentation attendees were then given a short survey in person aimed at their satisfaction with the sites ability to perform in the identified areas of need. This survey was given immediately following the presentation and then 2 months later to better understand if the issues were remaining stagnant, worsening, or improving.

**Outcomes Measurement**

To measure the outcomes of this DNP, Project the following methods were used: surveys for the needs assessment portion, a database to record answers from the survey, and post education intervention surveys. The needs assessment survey was developed by the DNP student and consisted of open-ended questions which allowed the participants to elaborate on what their perceived needs were for end of life care transitions. This survey also included multiple-choice questions to better understand how comfortable participants were with end of life care as well as how often they cared for patients at the end of life. Additionally, there was a fill in the blank question and multiple-choice questions to obtain demographic information about the participants. To organize the open-ended questions and gather useful data the answers were categorized by topic and the use of recurring words summarized as part of analyses.
The post education surveys used Likert rating scales to understand how satisfied participants were with the topics most frequently identified through the needs assessment survey. The intention of this method was to understand if participant satisfaction improved in each area after they were given evidence-based information on the topic and time to incorporate that knowledge into practice. Giving the post surveys at two different time points, immediately following the presentation and then two months later, provided the opportunity to see if time, in addition to new information, improved participant satisfaction on a topic.

**Data Collection Procedures**

Needs assessment surveys were sent to employees by email so that they could complete them at their convenience. The demographic data was analyzed by frequency. The data collected in this needs assessment on subject views of end of life care barriers and facilitators is descriptive and based on a small group of IDT members.

Post educational intervention survey data was also descriptive. This is an analysis that attempted to understand how satisfied participants are in their individual ability and their sites ability to perform in the topic of the educational intervention. The post surveys aimed to understand how effective the intervention was to address the identified area of need. Post surveys provided the opportunity to identify continued barriers to care transitions that potentially can be addressed by future informational interventions. Post-educational intervention surveys were gathered immediately after the educational presentation and two months later. The answers were analyzed so that subject satisfaction of the content could be recorded, and the impact of the educational intervention could be measured. The immediate post survey and 2-month post survey were compared to evaluate for a change in satisfaction after the intervention. Further
comparative analysis, such as a t-test, was not performed because the sample size was not robust enough to ensure the validity of such an assessment.

**Ethical Considerations/Protection of Human Subjects**

An IRB determination form was submitted to the participating university Human Research Protection office to ensure that this project followed the Internal Review Board (IRB) requirements prior to initiating the DNP project. The Office of Human Research Protection determined that this project did not require IRB approval as it did not meet the definition of human subject research (See Appendix F for Memorandum). The participants were IDT staff members and they were provided information on this project via a consent form that fully explained the project goals, risks, and benefits and that participation was voluntary throughout the project (See Appendix G for the Consent Form). Staff were protected from any retribution their feedback may cause because their survey responses have been kept confidential and subject responses remained anonymous.

**Results**

The needs assessment surveys were completed by a total of 11 participants between September 18, 2018 and October 9, 2018. Of those participants 3 (27%) were nurses, 3 (27%) were physical therapists, 2 (18%) were occupational therapists, 1 (9%) was a nutritionist/dietician, and 1 (9%) was occupation unknown. One hundred percent of participants indicated that they had been working at the site for 5 years or less with 5 (45%) having worked there for 0-2 years and 6 (55%) having worked there for 3-5 years. The results were varied for how long the participants had been working with patients who were transitioning to end of life care. One (9%) participant had worked with these patients for 0-2 years, 3 (27%) had worked
with them for 3-5 years, 2 (18%) for 5-10 years, 2 (18%) for 10-20 years, and 3 (27%) for 20 or more years. When asked how often participants care for patients transitioning to end of life care, 2 (18%) indicated it was often, at least weekly or biweekly, 8 (73%) cared for them sometimes, every 1-2 months, and 1 (9%) cared for these patients rarely, 1-2 times per year.

The needs assessment survey aimed to evaluate subject level of comfort with transitioning patients to end of life care and 4 (36%) were somewhat comfortable and 7 (64%) were very comfortable, while no participants did not feel comfortable with this task. The subjects were then asked if they felt patients were being transitioned to end of life care in a timely manner. Five (45%) participants stated that they were transitioned too late, 4 (36%) felt it was at just the right time and 2 (18%) participants were unsure.

The participants were asked to elaborate in open ended answers what they felt were barriers as well as enablers to patient care transitions to end of life care for themselves as individuals and collectively as a site. The answers were varied but some common themes emerged. For areas of improvement for individuals 3 (27%) individuals left the answer blank or said there was nothing that could be done to improve. Three (27%) individuals remarked that communication with families or goals of care (GOC) conversations can occur earlier and more often. Three (27%) individuals felt that improved medication management skills were needed. Other areas noted include team coordination and better positioning of patients for improved comfort.

Participants described how they can improve as a site in similarly varied ways but with common themes emerged. Areas mentioned included; team coordination, communication with long term care facilities and hospitals, more in home care services needed, improved communication with patient’s providers, consistency of provider care, and establishing a
checklist or a clear process for what needs to occur to effectively transition to end of life care. Themes of interdisciplinary care team communication, GOC conversations, and medication management were mentioned as areas that needed improvement for individuals and the site.

To summarize the areas identified as barriers to effective care transitions communication and addressing patient comfort were the two most frequently mentioned items. General communication was mentioned 12 times with GOC communication being mentioned 3 times, interdisciplinary care team communication being mentioned 6 times and communication with families being mentioned 2 times. Addressing comfort and symptom management was noted 4 times. Figure 1 (see Appendix H) displays more detailed information on the words subjects used to describe barriers to care.

The participants also shared what they felt they did well as individuals and collectively. Providing comfort to patients, being respectful and supportive, patient safety, holistic approach, identifying changes in status, knowing the patient and providing the tools necessary to transition to end of life care in the home were all mentioned as strengths of individual participants. Goals of care conversations, communication with patients and their families, team collaboration, and family education were some skills that were noted as both strengths and areas for improvement.

Communication was mentioned 12 times in total as a barrier to care. This was the most frequently cited topic in the survey and thus was chosen as the broad theme of the evidence based educational intervention. This theme was divided into 4 smaller categories of technology and communication, goals of care communication, long term care communication and IDT communication. Following the presentation, a focus group was held to discuss participant thoughts and to plan on the sites next steps of action to address their areas of need. This presentation was made on December 14, 2018.
A total of 6 (55%) out of the 11 original subjects participated in the educational intervention. Of the 6 participants, only 5 could complete the surveys immediately following the intervention and of those 2 completed the post surveys at the 2-month mark. The post surveys focused on subject satisfaction of their ability to perform in the areas addressed by the educational intervention. See Figure 2 for the survey results immediately following the educational intervention and see Figure 3 for the survey results 2-month post intervention (See Appendix I for Figure 2 and Figure 3). Notable results include that participants had the greatest satisfaction on communication within the IDT on transitioning patients to end of life care in the post intervention survey at both time points. At least 20% of participants remarked that they were dissatisfied in communication with long term care facilities and in the use of technology for communication with IDT members and patient loved ones on end of life care transitions. This dissatisfaction was consistent in the immediate post surveys and the 2-month post surveys.

**Discussion**

The needs assessment portion of this project was beneficial in that it provided a better understanding of what can be improved upon to make patient transitions to end of life care more effective. This was viewed through the lens of what individuals feel are personal barriers and what they feel are group barriers to care. Staff most often identified communication and medication management as areas that are lacking in end of life care transitions. Conversely, they felt that their strengths were in knowing their patients well and providing support and comfort to the patients and their loved ones during this time of grave need.

While the topic of communication was the most often identified barrier to good care, the responses on communication were varied and complex. Some felt that goals of care conversations with patients and their families need to be improved while others felt that it was
communication between the IDT and long-term care facilities that is the issue. There were individuals who felt that a lack of continuity in care teams was disrupting communication lines whereas others described provider accessibility as the issue. Furthermore, there was disagreement on whether communication was a barrier or a strength, as evidenced by subjects who answered IDT collaboration or goals of care meetings as things that individuals and the site do well. This should not be seen as conflicting data but rather as a reality that speaks to the fact that communication is multi-dimensional and that strategies to improve upon this needs to also be multi-dimensional.

The literature affirms this as seen in previously performed needs assessments that identified not only communication between patients and providers as needing improvement but also between interdisciplinary staff, between staff and family, and between the various care facilities involved in the patients’ care (Coats et al., 2017; Namaslveyam & Barnett, 2016). It should also be considered that while a site may struggle in certain aspects of communication they might also do very well in other areas. For example, a site may have an excellent rapport with their patients that enables them to have open and frank discussions with patients and each other but still be delayed in having goals of care conversations with their patients. This points to there not just being one solution to address communication and end of life care transitions but rather many solutions that can address all the aspects that need improvement while enhancing the areas where a site already excels.

During the time spent with this site it became evident that their structure and functioning were unique and that they knew their patients and their needs better than any person coming from outside the organization could. It is because of this that it was a challenge to create an educational intervention that addressed the needs of the facility. To refer to Lewin’s change
theory the challenge was in the transition from the Unfreezing stage to the Change stage (Lewin, 1951). Lewin provides a guideline for how to address such a hurdle in encouraging the leader to empower their peers to incite change. Subject empowerment was accomplished by directing the content of the educational intervention towards a theme that the subjects identified themselves.

When the educational intervention was being developed the emphasis was on the areas that the subjects themselves had predominantly identified as areas of need. Communication was the focus of the presentation and to address the multi-faceted nature of the topic it was broken down into four areas; technology and communication, goals of care communication, long term care communication, and IDT communication. After a review of the research on these areas was presented, much of the time was spent having a focus group style discussion on the survey results, the information presented, and where the site goes from here to improve and sustain this critical aspect of care.

The presentation allowed for the focus group to be structured and on topic. This was important considering the varied responses and opinions of the group members. The participants discussed, in specific terms, what they could do to improve their communication strategies for the benefit of patients who need to transition to end of life care. Incorporating goals of care conversation guides, such as the Serious Illness Conversation Guide (Ariadne Labs, 2019), into the patients EMR was introduced. This would allow providers to have a tool to help them with the content of the conversation as well as documenting the conversation for other team members to know what was addressed and when. Additionally, developing a document of communication tools for patients and their families including online resources and books was proposed. After coming up with these goals the group determined that they should develop an end of life and palliative care working group to ensure that these solutions were actualized. In keeping with
Lewin’s idea of empowerment to boost change, the focus group allowed the team to come up with their own plan to move forward from this project and sustain momentum. This working group will be an important step in the Refreezing stage of the theory because it will allow for a culture change at the site that fosters good habits and an openness to new ideas.

The post surveys could have assisted in knowing whether the educational intervention and focus group was effective in the longer term. For example, for this site if they were to create a working group and achieve their goals on the subject’s satisfaction on the site’s communication abilities surrounding end of life care may have improved. Unfortunately, the responses for the 2-month post survey were low and therefore the comparison needed to evaluate for change could not be done. The site does now have a foundation of information that they can use beyond this project to evaluate for positive changes as they continue the important work of aiding in effective care transitions for patients who are at the end of life.

**Strengths.** The staff at the site were utilized as a resource for understanding how the site operates and what their current practices are. There are staff members on the IDT who specialize in hospice care and provided an informed understanding for what is and what is not working in their current system. Additionally, the staff was highly motivated to improve these processes for their patients and willing to collaborate on this project.

**Limitations.** Barriers included finding the time during busy schedules of IDT members for survey completion and for the educational intervention. This was addressed during one of the IDT meetings to determine the most convenient times for participants to be available. Despite this, only 55% of subjects could attend the educational intervention and only 45% and 18% of subjects completed the immediate post intervention survey and 2-month post intervention survey, respectively.
Conclusion

One of the most difficult decisions a patient will make in their lifetime is deciding to stop life extending treatments and accept end of life care. However, research shows that doing so can lead to better outcomes and quality of life for patients and their loved ones. Health care providers play an integral role in helping patients to make the transition of end of life care but the ability to do so remains challenging. Due to a variety of reasons most patients do not effectively transition to hospice care that is meant to ease the suffering experienced at the end of life. To make improvements on this it is essential to first understand what the site-specific barriers to care are. This project has shown that it is feasible to perform a needs assessment with an interdisciplinary care team on the topic of end of life care transitions. Needs assessments can build knowledge that will more effectively direct intervention strategies aimed at improving access to appropriate treatment for those who are experiencing the end of life. Furthermore, such interventions may prove to be more impactful because they were identified by those who are directly involved in their creation.
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http://www.pace4you.org/.


Appendix A

Nursing Theory: Lewin’s Change Model

**LEWIN’S CHANGE MODEL**
Lewin’s Three Stage Change Process – Practical Steps

- **Unfreeze**
  - Determines what needs to change
  - Ensure there is strong support from management
  - Create the need for change
  - Manage and understand the doubts and concerns

- **Change**
  - Communicate often
  - Dispel rumors
  - Empower action
  - Involve people in the process

- **Refreeze**
  - Anchor the changes into the culture
  - Develop ways to sustain the change
  - Provide support and training
  - Celebrate successes
Appendix B

Nursing Theory: Lee Geropalliative Caring Model
Appendix C

Needs Assessment Survey

1. What is your specialty?

2. How long have you worked at this site?
   - 0-2 years
   - 3-5 years
   - 6-10 years
   - 10-15 years
   - 15-20 years
   - More than 20 years

3. How often do you care for patients who are transitioning to end of life care?
   - Always (Daily)
   - Often (Weekly or Biweekly)
   - Sometimes (Every 1-2 months)
   - Rarely (Once or twice per year)
   - Never

4. How comfortable do you feel caring for patients who are transitioning to end of life care?
   - Very Comfortable
   - Somewhat Comfortable
   - Not Comfortable
5. Do you think patients with this PACE program are transitioned to end of life care too late, too early, or at just the right time?
   - Too late
   - Too early
   - Just the right time
   - Unsure

6. What do you feel you need improvement on in caring for patients who are transitioning to end of life care?

7. What do you think your job site needs improvement on in caring for patients who transitioning to end of life care?

8. What do you feel you do well when caring for patients who are transitioning to end of life care?

9. What do you think your job site as a whole does well with when caring for patients who transitioning to end of life care?
Appendix D

Post-Survey

1. How satisfied are you with your site’s communication with patients and their loved ones during end of life transitions?
   - Very satisfied
   - Satisfied
   - Neither satisfied nor dissatisfied
   - Dissatisfied
   - Very dissatisfied

2. How satisfied are you with your site’s use of technology to communicate with each other for patient end of life transition needs?
   - Very satisfied
   - Satisfied
   - Neither satisfied nor dissatisfied
   - Dissatisfied
   - Very dissatisfied

3. How satisfied are you with your site’s use of technology to communicate with patients and loved ones for end of life transition needs?
   - Very satisfied
   - Satisfied
   - Neither satisfied nor dissatisfied
   - Dissatisfied
   - Very dissatisfied

4. How satisfied are you with your site having goals of care conversation with patients and their loved ones?
   - Very satisfied
   - Satisfied
   - Neither satisfied nor dissatisfied
   - Dissatisfied
   - Very dissatisfied

5. How satisfied are you with your site communicating end of life transitioning to long term care facilities/hospitals?
   - Very satisfied
   - Satisfied
   - Neither satisfied nor dissatisfied
   - Dissatisfied
   - Very dissatisfied

6. How satisfied are you with your site’s communication amongst the interdisciplinary team regarding patients who are transitioning to end of life care?
   - Very satisfied
   - Satisfied
   - Neither satisfied nor dissatisfied
   - Dissatisfied
   - Very dissatisfied
Appendix E

PowerPoint Slides

TIMELY TRANSITIONING TO HOSPICE: A NEEDS ASSESSMENT WITH A PACE PROGRAM TO IMPROVE END OF LIFE CARE.

Kristina Kelley
University of Massachusetts at Amherst

OUTLINE

- Review results from Needs Assessment Surveys
- Pre-Surveys
- Review evidence-based practices (EBP) on communication with LTC facilities
- Discussion
- Post Surveys
- N= 11
- 3 Nurses
- 3 PT
- 2 OT
- 1 Administration
- 1 Nutritionist/Dietician
- 1 Unknown
How many years have you spent during your career caring for patients who are transitioning to end of life care?

Answered: 11  Skipped: 0

- 0-2 years: 3%
- 3-5 years: 10%
- 5-10 years: 20%
- 10-20 years: 35%
- 20+ years: 20%

How often do you care for patients who are transitioning to end of life care?

Answered: 15  Skipped: 0

- Always (daily): 20%
- Often (weekly or bi-weekly): 20%
- Sometimes (monthly): 60%
- Nearly (once a year or more): 20%
- Never: 0%
**Q5**

How comfortable do you feel caring for patients who are transitioning to end of life care?

Answered: 11  Skipped: 0

- Very Comfortable
- Somewhat Comfortable
- Not Comfortable

**Q6**

Do you think patients with this PACE program are transitioned to end of life care too late, too early, or at just the right time?

Answered: 11  Skipped: 0

- Too late
- Too early
- At the right time
- Unsure
WHAT DO YOU FEEL YOU NEED IMPROVEMENT ON IN CARING FOR PATIENTS WHO ARE TRANSITIONING TO END OF LIFE CARE?

- Team coordination
- Communicating with families
- Positioning and comfort
- Pain management
- Medication management (Kit)
- ID Family who will manage pt needs
- Communication about pt wishes earlier
- Communication on pt goals earlier
- Education on medications

WHAT DO YOU THINK YOUR JOB SITE NEEDS IMPROVEMENT ON IN CARING FOR PATIENTS WHO TRANSITIONING TO END OF LIFE CARE?

- Team coordination
- Communication with LTC
- In home care services including aides to asst family
- Pain management
- Nursing visits at EOL
- Communication with nurses who are giving IHC
- Access to clinic and providers if pt changes
- Clear process – GOC, expectations
- Consistent health care providers
- Support pts in asst living facilities
- Communicate during hospitalization
- EOL checklist
- Support for pts in the hospital/LTC
**BARRIERS TO EOL TRANSITIONS**

- Communication was mentioned 12 times
- Addressing patient comfort and symptom management was mentioned 4 times

**WHAT DO YOU FEEL YOU DO WELL WHEN CARING FOR PATIENTS WHO ARE TRANSITIONING TO END OF LIFE CARE?**

- Relaxation
- Compassion
- Home care
- Comfort
- Knowing pt
- Support
- Respect
- Providing equipment
- GOC meetings
- Pt safety
- Education


- Good communication between health care workers, patients, and families plays a key role in end of life care outcomes
- Communication on GO, advance directives, family care taker, symptom management
- Some of the challenges include; the difficult nature of the topic, the many players involved, time
- Today we have become increasingly reliant on technology for communication. Is there a role here for using technology to communicate end of life care needs?

- Link documentation to EOL preferences
- Promote health literacy
- Communicate patient symptoms in real time
- Guide goals of care conversations and document
- Death Over Dinner

*Death Over Dinner, 2018; Ostherr, Killoran, Shegog, & Bruera, 2016*
EB SUPPORTED TECH IN EOL

- Telehealth, tele monitoring
- Text messaging
- Email prompt
- Website based monitoring program
- Electronic based medical record

Ostherr, Killoran, Shegog, & Eduardo, 2016

GOALS OF CARE COMMUNICATION

- Evidence based research efforts have produced numerous GOC communication guides.

<table>
<thead>
<tr>
<th>2. If you were to get sicker, what would be most important to you?</th>
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<tr>
<td>Problem</td>
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</tbody>
</table>

Bekelman, et al. 2017
GOC COMMUNICATION AND LOVED ONES

- Study in North Carolina looking at GOC conversations with loved ones of patients who have advanced dementia.
- RCT
- Intervention group watched an 18-minute video followed by a structured conversation with medical team.
- Received a written guide “Questions to Consider in Care Planning”
- Medical staff were also given training using a video, discussion guide, and reminders to meet with participants
- Intervention group have higher satisfaction in end-of-life communication

Hanson, et al., 2017

GOC COMMUNICATION REMINDERS

- Study that looked at sending an alert via the EMR
- Intervention included a training session and EMR alert with EMR communication tool.
- Alert was sent 1 time, on pt. admission
- The intervention resulted in an increase in the number of patients who had documented GOC conversations.

Haley, et al., 2017
• Study that utilized Family Care Conferences (FCC’s)
• Training done at the start which utilized a video “All on the Same Page”
• FCC triggered when they scored 40% or less on the Palliative Performance Scale.
• Meetings facilitated by a leader and were multidisciplinary including LTC representative, SW, nursing, physicians, etc.
• Family filled out a questionnaire in advance
• Conversation and subsequent documentation guided by a resource that focuses on 8 domains: disease mgmt., physical, psychosocial, social, practical, EOL, spiritual, and loss/bereavement

Durepos, et al., 2018

• The IDT meeting has been identified as a setting that
  improves communication in health care.
• How to improve collaboration when the IDT is already in place?
• Measure collaboration to determine barriers to effective communication
  • Index of Interdisciplinary Collaboration
  • Multidisciplinary Collaboration Instrument
  • Role Perceptions Questionnaire

Lyndon & Cashell, 2017; Yoo, et al., 2013
THE INTERDISCIPLINARY TEAM MEETING

- The best IDT meetings benefit from:
  - Structure (checklist, agenda)
  - Patient-centeredness
  - Effective leadership

Van Dogen, et al., 2016

DISCUSSION

Thoughts? Where do we go from here?
REFERENCES


Memorandum – Not Human Subjects Research Determination

Date: August 23, 2018

To: Kristina Kelley, College of Nursing

Project Title: Transitioning to Hospice with a PACE Program

IRB Determination Number: 18-155

The Human Research Protection Office (HRPO) has evaluated the above named project and has made the following determination based on the information provided to our office:

☐ The proposed project does not involve research that obtains information about living individuals [45 CFR 46.102(f)].

☐ The proposed project does not involve intervention or interaction with individuals OR does not use identifiable private information [45 CFR 46.102(f)(1),(2)].

☒ The proposed project does not meet the definition of human subject research under federal regulations [45 CFR 46.102(d)].

Submission of an Application to UMass Amherst IRB is not required.

Note: This determination applies only to the activities described in the submission. If there are changes to the activities described in this submission, please submit a new determination form to the HRPO prior to initiating any changes.

A project determined as “Not Human Subjects Research”, must still be conducted in accordance with the ethical principles outlined in the Belmont Report: respect for persons, beneficence, and justice. Researchers must also comply with all applicable federal, state and local regulations as well as UMass Amherst Policies and procedures which may include obtaining approval of your activities from other institutions or entities.

Please do not hesitate to call us at 413-545-3428 or email humansubjects@ora.umass.edu if you have any questions.

Iris L. Jenkins, Assistant Director
Human Research Protection Office
Appendix G

Consent Form

Consent for Participation in Interview Research

I volunteer to participate in a research project conducted by Kristina Kelley from the University of Massachusetts, Amherst. I understand that the project is designed to gather information on the care of patients who are receiving treatment at the end of life. I will complete a survey to assess the needs of myself and my job site in caring for patients at the end of life. I will then participate in an educational session on the topic of end of life care and complete a survey after that session on my knowledge of the topic.

1. My participation in this project is voluntary. I understand that I will not be paid for my participation. I may withdraw and discontinue participation at any time without penalty. If I decline to participate or withdraw from the study, no one at my job site will be told.

2. I understand that most participants will find the surveys and educational session interesting and thought-provoking. If, however, I feel uncomfortable in any way during this process I have the right to decline participation in the education session and to answer survey questions.

3. I understand that the researcher will not identify me by name in any reports using information obtained from these surveys, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions.

4. Faculty and administrators from my campus will neither be present at the interview nor have access to raw notes or transcripts. This precaution will prevent my individual comments from having any negative repercussions.

5. I understand that this research study has been reviewed and approved by the Institutional Review Board (IRB) for Studies Involving Human Subjects: Behavioral Sciences Committee at the University of Massachusetts, Amherst. For research problems or questions regarding subjects, the Institutional Review Board may be contacted through [information of the contact person at IRB office of UMass].

6. I have read and understand the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

7. I have been given a copy of this consent form.

____________________________ ________________________
My Signature Date

____________________________ ________________________
My Printed Name Signature of the Investigator
Appendix H

Figure 1 Words used to describe general barriers to end of life care transitions.
Appendix I

Figure 2 Satisfaction Survey Immediate Post Intervention

Figure 3 Satisfaction Survey 2 Month Post Intervention