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Addressing Common Misperceptions About Palliative Care

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Author Note

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Abstract

The Central Coast Visiting Nurse Association and Hospice provides home medical care and end-of-life services to people across Monterey, San Benito, Santa Cruz, and Santa Clara counties. This project was designed to address the problem of underuse of hospice and palliative care services. Contributing factors include misconceptions about hospice and palliative care, negative stereotypes associated with end-of-life methodology, and fear and discomfort in facing the death of loved ones. These factors frequently result in negative consequences, including late admission to programs, greater financial costs to patients and families, and greater discomfort for end-of-life patients. The project consists of an educational video intended for individuals and families transitioning into palliative care. The video addresses common misperceptions and frequently-asked questions. Responses gathered from feedback at the agency indicated favorability towards the video, and interest in potential implementation in the agency's website. Recommendations include ensuring widespread accessibility of content through use of closed captions or translations in multiple languages, inclusion of visual aids, and pairing video with other website content aimed at increasing understanding and accessibility.

Keywords: Palliative care, hospice care, end-of-life planning, death and dying

Agency & Communities Served

The agency served in this project is the Central Coast Visiting Nurse Association (VNA) and Hospice. The VNA is a healthcare non-profit serving Monterey, San Benito, Santa Cruz, and South Santa Clara counties (About VNA, 2020). Their mission statement is, "VNA is dedicated to providing the highest quality health care to residents of the Central Coast by meeting their individual needs in a caring, effective, honorable, and accessible manner" (About VNA, 2020).

The agency has several programs, including a home health program that provides services such as cardiac care, diabetic care, orthopedic care, and palliative care, a hospice program, and a community health program that provides immunizations, flu clinics, travel health and school health services (About VNA, 2020). This capstone will focus on the hospice and palliative care programs at the agency.

The hospice and palliative care programs at VNA are specialized care programs for people facing serious illnesses, their families, and their caregivers. In both programs the focus is to improve quality of life for patients and families by addressing their physical, emotional, social and spiritual needs (Palliative Care Program, 2019, Hospice Care, 2021). The palliative care program differs from the hospice program in that patients in palliative care are still seeking treatment for their illness, while people in hospice have a clinical diagnosis of having six-months-or-less to live, and focus on managing pain and maximizing quality of life, rather than extending it. Both programs take an interdisciplinary approach to care, with healthcare teams tailored to meet the needs of the patients. These teams may include physicians, nurses, case managers, medical social workers, personal care and hospice aides, spiritual care coordinators, bereavement coordinators, and volunteers (Palliative Care Program, 2019, Hospice Care, 2021).

Central Coast VNA and Hospice serves several hundred people across their various programs. Patients in hospice and palliative care live primarily in Monterey County, with lower numbers in San Benito County, Santa Clara County, and Santa Cruz County. While the programs accept patients of any age, and have served patients as young as 2-5, the majority of patients are over 60 years old, with the highest numbers of patients being over 80. The majority of patients identified as White or Hispanic, with lower numbers of Asian people, Black people, and Pacific Islanders (VNA Demographics, 2019-2020).

Problem Description

The problem that is addressed in this capstone project is the underuse of hospice and palliative services. Studies have shown that, although hospice and palliative care programs have been demonstrated to produce excellent outcomes in symptom management, patient and family satisfaction, and reduction of healthcare costs, these services are continually undersused in the United States (Fine, 2018). Among patients that are admitted to hospitals, fewer than 5% are seen by a palliative care team, and only half of people who die in the United States receive hospice care, despite statistics showing that the leading causes of death in the United States are long-term illnesses such as heart disease and cancer (Shalev et. al., 2017, CDC, 2021). The underuse of hospice and palliative services is a growing problem, as the U.S. population continues to get older and the percentage of people living longer with serious illness increases.

Contributing Factors

Some of the contributing factors to the underuse of hospice and palliative care include misconceptions about hospice and palliative care, negative stereotypes associated with end-of-life methodology, and fear and discomfort in facing the death of loved ones. A 2016 study on perceptions of palliative care found that:

> Palliative care was perceived as a passive form of care, when there was “nothing else that can be done” and “no hope.” There was a strong association with being incapacitated, bedridden and incapable of self-care, and with care in “places that you never get out [of] again.” (Zimmerman, 2016, p.3)

The study found that these “[negative] attitudes toward palliative care” were prevalent among patients and caregivers, and frequently contributed to late referrals from physicians (Zimmerman, 2016, p.1). Further studies have supported the effects of these misconceptions on palliative and hospice care use. A 2019 report showed that:

> Patients and family members who have negative attitudes towards palliative care *at the time of diagnosis* may be similarly unlikely to ask for a consultation and less likely to accept a consultation or services if offered. These pre-existing beliefs can influence formal directives, such as advance care plans, and affect the care options available to patients by shaping provider decision making and patient-provider conversations. (Taber, 2019, p. 1-2)

This negatively affects use of services, as patients and families are less likely to receive accurate information regarding hospice and palliative care, and include these services in their end-of-life planning.

Other negative stereotypes against methodology used during end-of-life, such as the use of morphine, were found to potentially “cause patients to overestimate likelihood of addiction and death, leading them to fear these medications and avoid palliative care services, such as pain management” (Taber, 2019, p.2). These kinds of negative associations with end-of-life services can lead people to fear methods of pain management, delaying their implementation and ultimately causing greater pain to the patient.

The third contributing factor to the underuse of hospice and palliative services is fear and discomfort in facing the death of loved ones or oneself. A study on perceptions of palliative care in participants and caregivers found that participants, “described feeling ‘frightened’ and ‘shocked’ when palliative care was introduced… Avoidance and resistance were common reactions…many stated that they tried not to think about palliative care, and did not want to ‘dwell on the negative’” (Zimmerman, 2016, p.4). These avoidance reactions, while understandable, do not help families and patients to properly plan for care. People may put off entering palliative and hospice programs for too long, preventing them from receiving health care, mental health care, and emotional support that could be extremely beneficial to them.

Consequences

Consequences of the underuse of hospice and palliative care services include late admission to programs, greater financial costs to patients and families, and greater discomfort for end-of-life patients. Reports from the National Hospice and Palliative Care Organization (NHPCO) show that many people access hospice care late in the course of an illness. According to the NHPCO, 53.8% of Medicare beneficiaries received hospice care for 30 days or fewer in 2018, and 27.9% of beneficiaries received hospice care for fewer than 7 days (Hospice Facts and Figures, 2020). These numbers are concerning, as studies have shown that enrollment of at least three months is necessary to receive optimal services and benefits (Nahapetyan, 2019, p.1). This delay in enrolling means that, even when people do eventually get access to hospice and palliative services, they are unable to receive the full benefits of the comprehensive physical, emotional, social, and spiritual care these services provide.

The underuse of hospice and palliative services can also result in greater financial costs for patients and families. Hospice is completely covered by Medicare, Medicaid, and most private insurances, which can help significantly to alleviate the financial stress of high-cost hospital and home health care for families (Hospice Care, 2021). However, because of the underuse of hospice and palliative services, families do not receive these benefits, and must shoulder the costs themselves.

Finally, underutilization of hospice and palliative care services can result in greater discomfort for end-of-life patients, who are unable to receive the improved symptom management and quality-of-life-focused care that hospice and palliative care offer (Fine, 2018). Rather than focusing simply on disease treatment for patients, hospice and palliative care work with patients and families to meet their individual needs. Pain management and symptom management become the primary concerns, ensuring that patients are able to make the most of their remaining time, as well as spending that time as much as possible in their homes (Hospice Care, 2021).

Problem Model

Contributing Factors	Problem	Consequences
Misperceptions about hospice and palliative care	Underuse of hospice and palliative services	Late admission to programs
Negative stereotypes associated with end-of-life methodology		Greater financial costs for patients and families
Fear and discomfort in facing the death of loved ones and self		Greater discomfort for end-of-life patients

Capstone Project Description and Justification

Capstone Project

This capstone project consists of an educational video for individuals and families transitioning into hospice and palliative care. It is designed to help address the misconceptions, stereotypes, and fears that contribute to the underuse of hospice and palliative care services. The capstone aims to address these issues at a local, agency level.

Project Purpose

This educational video is designed to address the contributing factor of the misperceptions about hospice and palliative care that lead to the underuse of hospice and palliative services. The video addresses some of the most common misconceptions and questions that people run into when entering hospice and palliative care, and works to address these so that people can have improved insight into hospice and palliative care and the benefits that they can receive from these services. The information in the capstone aims to reduce misconceptions and lead to a better understanding of hospice and palliative care in the community, in order to expand their use and benefit more people.

Project Justification

Studies have shown that education can yield significant impacts in reducing negative misperceptions and improving people's perceptions of complicated and stigmatized issues like those dealt with in hospice and palliative care, including mental health and dementia (Benbow 2012, p.3, Corrigan, 2012, p. 967-968). Other research into the use of technology in learning has found that:

> Working memory has two channels for information acquisition and processing: a visual/pictorial channel and an auditory/verbal-processing channel...although each channel has limited capacity, the use of the two channels can facilitate the integration of new information into existing cognitive structures (Brame, 2016).

The use of a video in this capstone aims to help engage these multiple learning channels in order to maximize information retention for visitors to the agency webpage and video viewers, as well as making the learning materials in the webpage accessible to a wider audience, if any visitors have visual or auditory impairments that make accessing one of the information formats difficult. The video is designed to be paired with agency website written content, and would ideally be readily findable from the VNA agency website, so that people searching for more information on hospice and palliative care can easily find it.

Assessment Plan

The agency mentor and members of the palliative and hospice teams reviewed the script for the video prior to its creation, in order to ensure that the information included is accurate and useful to the agency. Following completion of the finalized video, the final capstone materials' effectiveness were also evaluated by agency staff. Evaluation of the completed project was accomplished through feedback surveys that are sent out to hospice and palliative care team members. If implemented on the agency's website, the effectiveness of this capstone project in the community could be measured via a one-click yes or no question for users: "Did you find this information useful?" Further, there could be an optional, open-ended feedback and suggestions field. These measures could be used to gauge whether visitors found the information they learned regarding hospice and palliative care on the web page useful, and bring to light any areas that need to be expanded upon. A hit counter on the web page and video could help to measure the percentage of webpage and video visitors who responded to the survey.

Expected Outcomes

The capstone aimed to receive feedback from agency surveys reflecting that 70% or more of survey respondents found that the information contained in the materials was useful and would be a positive addition to the agency's website. Achieving these results would mean that the video had accomplished the goal of creating content that could meaningfully expand understanding of hospice and palliative care in the community, and that patients and their loved ones could be able to use to make more informed decisions regarding participation. As the video aims to be an ongoing resource at the agency, the hope is that this capstone would continue to be used and to promote greater understanding and use of hospice and palliative care in years to come.

Project Implementation

Implementation of this capstone project began during March of 2021, with meetings with Interdisciplinary Teams at the agency to connect with care team members and learn more about the way hospice and palliative care work. This was followed by further research into common misperceptions of hospice and palliative care in the community and on video production and editing during the summer of 2021.

In September of 2021 a survey was designed for this project and sent out to Interdisciplinary Team members to help determine some of the most common questions and misconceptions people at the agency encounter. Based on the results of the survey, it was determined that there was greater need for informational materials in the Palliative Care team than in the Hospice Care team, and common issues that they experienced were identified. With these results, planning for the video, including plans for the script, was conducted during September 2021.

During this planning process, it became clear that the initially planned distribution and assessment plan in the community would be impossible to fulfill in the project's timeline. Together with the agency mentor, the project was altered from a completed video that would go directly on the agency's website to a proof-of-concept presentation and mockup, which could be presented to employees and agency board members to demonstrate the capstone project's usefulness, and feedback from agency members would be used to assess the project's effectiveness.

With this revised action plan in place, an initial script was created for the video in early October. Agency members, including the agency mentor and a palliative care support specialist, were consulted to ensure information presented was accurate and useful. Following this, an initial draft of the video was shot in mid-October. This video was included in a brief PowerPoint presentation which explained the capstone project's background, and purpose, and would serve as a top line presentation to be easily shown agency members and members of the board for approval. The draft of this PowerPoint presentation and video, after receiving approval from the agency mentor, was shown to the organization's CEO for further feedback and approval in late October. Based on her feedback, a final script, version of the video, and PowerPoint was completed in early November. This final presentation was presented to members of the palliative care team, agency volunteers, and agency board members. Feedback was collected from these agency members to assess the project's reception and effectiveness in late November 2021. A detailed implementation plan and timeline can be seen in the Scope of Work section in Appendix A.

Project Results

Although the initial plan for the video was to create a video that would be attached to the agency's website, as planning and research continued, it became clear that this would be much more complicated to implement than originally thought. The agency website and materials are maintained and created by an outside agency, which would need to create their own version of the capstone content. Additionally, any new additions to the agency website must go through a process or receiving approval from the organization's board. These components could take many months to complete, and would be beyond the scope of this project. Therefore, working with the agency mentor, a new plan was developed to create the project as a top line presentation, which could be shown to agency employees and board members to demonstrate the need for and usefulness of the project's idea. The materials created would serve as a proof-of-concept for any official materials the agency would create. Feedback from agency members was used to assess the project's effectiveness.

Results from the initial survey sent to Hospice and Palliative Care Team members were limited, but a greater response rate from Palliative Care Team members indicated greater need and interest in this area. The surveys that were received identified common areas that agency members encountered when people were entering palliative services, including confusion concerning differences between hospice and palliative care and misunderstandings that entering care would cause patients to "die faster", people feeling overwhelmed, and divided goals of care, with families not understanding or agreeing with patient's wishes. A detailed breakdown of responses to the initial survey can be found in Appendix B.

Based on these responses an initial draft of the video was completed. This draft was then sent to agency mentor, and once, reviewed further sent on to a Palliative Support Specialist for content review. Her response to the initial draft was favorable, and she included feedback for improvements to be made to improve content. Following this feedback, revisions were made to include further information on services offered by VNA Palliative Care, and revisions in phrasing to include greater accuracy to agency wording and medical standards. This revised draft was used to create an initial draft of the video, which was embedded in a brief presentation including background information, goals, and sent to mentor for approval. Once approved, the draft was sent to the agency's CEO for review. Feedback on the draft video included approval for the video's concept and format. Suggestions for improvement included emphasizing that VNA Palliative care is a part of the agency's Home Health Care program, including more information on hospice care for comparison, and spotlighting how palliative care and hospice are both beneficial programs that can be beneficial to patients at different stages in their illness. This feedback was incorporated into another draft, which was further refined into the final draft. This last draft received mentor and CEO approval for inclusion in the final video.

With the final script approved, production on the final video was started. Several locations were scouted, but initial outdoor locations proved to have too many issues of background noise, lighting, and background distractions, and several drafts were rejected. An indoor temporary studio set up was finally selected for the video, in order to reduce distractions and better control conditions. Once created. The video was edited over the course of several days to create the final capstone material.

Although there was an initial plan to show the final project during an in-service meeting of volunteers and Interdisciplinary team members to collect feedback, this meeting had to be canceled due to scheduling conflicts. Instead, the video and background was sent out to agency members and volunteers via email, along with a short, three question feedback survey. While responses received were limited, all respondents reacted positively to the video's content and execution. Respondents indicated good interest in the addition of the video's content to the agency website and positive reactions to the video's execution, and provided useful suggestions for improvement, including the addition of visuals to reinforce content and create further visual interest, and the addition of subtitles in multiple languages to increase access to a wider audience. A more detailed breakdown of responses can be found in Appendix C.

Conclusion & Recommendations

Although responses received were limited due to the last-minute change in the plan for how responses were collected, all feedback received, both during production and after completion of the final product, indicated a strong interest in adapting the content for eventual inclusion in the agency's website. Although this has not been board-approved at this time, this interest indicates the general success of the project in creating a visual and auditory educational tool that has the potential to help patients and families better access information when transitioning into hospice care. It is hopeful at this time that the video may be used in the future to demonstrate the usefulness of this content and medium to the agency's board for inclusion in the agency's webpage.

Regardless of the project's ultimate implementation within the agency, there are other recommendations that can be implemented to increase accessibility of information and understanding of palliative care. Currently, the agency places great emphasis on their hospice program. However, they are also trying to grow their palliative care program, both in order to provide compassionate care earlier to people with serious illness (as palliative care can be offered without a six-months-or-fewer diagnosis), and to help bring people who are reluctant to take the leap into hospice care into VNA programs and position them better for when it is time to take the next step. Currently, their website includes a wealth of information on hospice, as well as videos and an inviting hospice webpage that emphasizes the many programs and services the program offers. However, the palliative care website is much less developed. Besides the implementation of this capstone, steps could also be taken to alter the VNA Palliative Care webpage to include more accessible language for patients and families who are not familiar with clinical terminology, promote information regarding Palliative Care to more prominent areas of the website – for example, moving information from the Palliative Care FAQ section to the main Palliative Care page to make it easier to find – and include language and imagery to make the webpage more personal, so that it accurately reflects the personal nature of the care the agency provides. If the capstone video is implemented, incorporating suggestions such as inclusive video aids and translations into other languages would also increase the information's accessibility.

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Appendix A

Scope of Work

Activities	Deliverables	Timeline/Deadlines	Supporting Staff
Attend Interdisciplinary team meetings	Gain better understanding of workings of hospice and palliative care teams and meet members	March 2021	Quinn Junhans
Research on common misperceptions and questions in hospice and palliative care	Determine other misperceptions that need to be addressed in community	May-August 2021	Quinn Junhans
Research on video creation and webpage creation	Gain background knowledge needed to create capstone materials	May- August 2021	
Create survey for Palliative and hospice teams	Determine some of the most common misperceptions dealt with	September 2021	Quinn Junhans
Assess results of survey	Gather data collected	September 2021	Quinn Junhans
Plan for video	Create a plan for how video will be shot	September 2021	Quinn Junhans
Initial script draft	Ensure that video content is correct and useful prior to shooting	October 2021	Quinn Junghans
Receive feedback on first draft and edit script	Create footage for video	October 2021	Quinn Junhans and Teresa Aguilar Lepe
Shoot first draft video	Create video materials for editing	October 2021	
Edit video	Create draft of video that will be used for capstone	October 2021	
Create draft of topline Powerpoint, with draft video embedded	Create a presentation that can be used to easily show the usefulness of this project	October 2021	Quinn Junghans

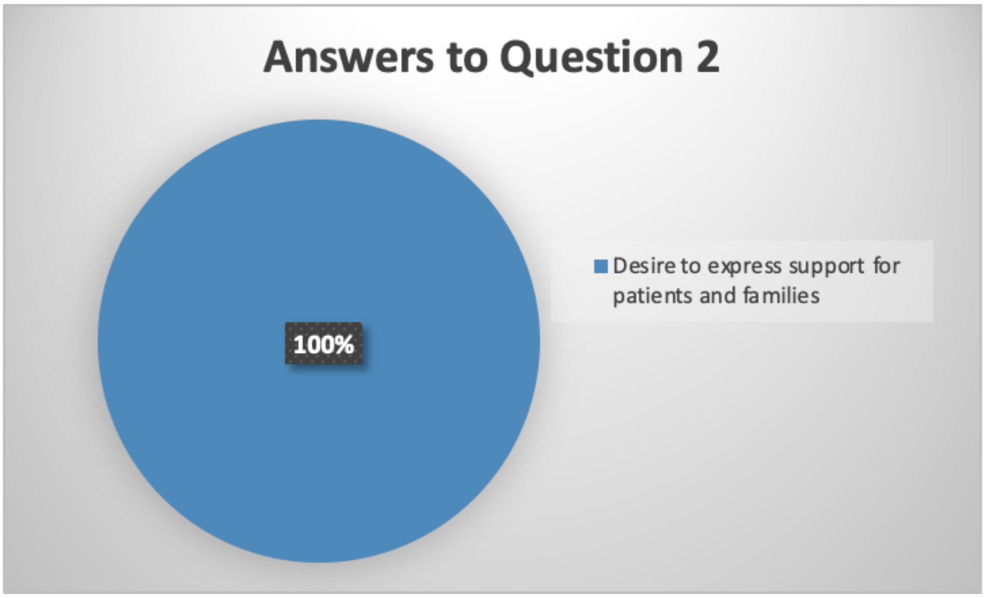
Receive feedback on initial presentation and video	Identify areas for improvement for final draft	October 2021	Quinn Junghans, Jane Russo
Edit presentation and video script	Reflect feedback for final presentation and video	October 2021	Quinn Junghans
Receive approval on final video script	Approve final materials for production	October 2021	Quinn Junghans
Shoot final video	Create materials for final video	November 2021	
Edit final video	Create final video to be used in capstone	November 2021	
Design survey to collect presentation feedback from agency members	Determine whether agency members find created capstone materials useful	November 2021	Quinn Junghans
Present final Powerpoint and video to agency members and distribute survey to collect feedback	Gather data to assess project reception and effectiveness	November	Quinn Junghans
Receive video and web page feedback at agency	Assess results of project	November 2021	Quinn Junhans

Appendix B

Responses to Initial Survey.

Question 1: List three issues that you often run into with people transitioning into care.

Question 2: What is one thing you wish you could tell everyone entering care?



Appendix C

Responses to Final Video

Questions:

1. Did you think the video's content would be a good addition to the VNA website?

2. Is there any section you would add to the video's content?

3. Are there any additional comments you would like to make about the video?