

Community Based Respite Care

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Community Based Respite Care

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Abstract

While hospice service usage remains approximately 47% in the United States (Wang et al., 2015), the use of community-based respite care is significantly lower among hospice patients. According to a study conducted by Plotzke & Pozniak (2015), respite care usage is around 3% among hospice patients in the United States. Additionally, caregiver stress remains a topic of concern among hospice patient's caregivers and families. This scholarly project utilized the Caregiver Self-Assessment Questionnaire (American Psychological Association, 2019) to identify stress levels among the caregivers of 18 patients admitted to hospice services. The project compared the results of caregivers for patients that utilized respite care services to the scores of caregivers for patients who did not utilize respite services. The project found that the use of community-based respite care was beneficial in reducing stress levels among caregivers.

Keywords: Community-based respite, hospice care, caregiver stress/strain.

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Community Based Respite Care

Chapter I. Introduction

Hospice care continues to be an underutilized benefit throughout the United States. In a retrospective analysis conducted by Wang et al. (2015), approximately 47% of patients utilized hospice during the last six months of life. Additionally, the percentage of hospice patients that utilize the respite benefit is significantly lower, at only 3% (Plotzke & Pozniak, 2015). In response, researchers have focused on evaluating the cause of the under-utilization of hospice's respite care benefit. The scholarly project aim is to further analyze whether community-based respite programs can decrease caregiver burnout and improve patient and family member satisfaction with the care the patient received while enrolled in hospice services.

Background & Significance

Currently the Centers for Medicare and Medicaid Services, CMS, (2019a) require that hospice beneficiaries utilize the hospice benefit in a Medicare-approved facility, such as an inpatient hospice facility, a skilled nursing facility, or a hospital. However, many patients and family members elect hospice enrollment due to the desire to remain in a home like setting. The Centers for Medicare and Medicaid Services (2019a) indicated that hospice focuses on providing comfort to the patient, and including the physical, emotional, mental, and spiritual needs. Lysaght and Ersek (2013) indicated that between 1989 and 2007, the number of home deaths increased nearly 10%, as home deaths were found to be associated with better symptom management and caregiver satisfaction when compared to deaths in inpatient units. Hospice patients have often had long battles with illness, and have a strong desire to avoid being treated in a hospital setting. As a result, many of hospice patients and their families are reluctant to use respite care in an effort to avoid being transferred to an inpatient facility. According to Plotzke

and Pozniak (2015), in 2012 only 3.5% of hospice beneficiaries utilized the inpatient respite benefit, indicating that many hospice caregivers are declining respite care for the patient. The Centers for Medicare and Medicaid (2019_a) indicated inpatient respite care benefit is intended to provide caregivers with an opportunity to rest and focus on self-care while their loved one is cared for at a trustworthy facility, and inpatient respite care can be utilized on an occasional basis, and for up to five days on each occurrence.

Needs Assessment

A needs assessment was completed through literature review and personal interviews with hospice executives. The assessment found that many hospice agencies have moved to community-based respite care. One hospice center in Phoenix, Arizona has purchased homes in neighborhoods throughout the valley where services, such as respite, continuous care, and inpatient symptom management, are provided (Hospice of the Valley, 2019). Hughes et al. (2019) found that respite care was felt to be beneficial to 85% of caregivers who utilized the service for their loved ones. Respite care is intended to provide periodic relief for caregivers, and reduce stress and burnout. Respite care has also been utilized for hospice patients when primary caregivers experience emergencies that prevent the caregiver from caring for the patient. Hospice executives have found that caregivers are reluctant to have patients admitted to inpatient facilities for respite services (F. Mwinyelle, personal communication, May 27, 2019). More emphasis needs to be placed on determining why respite utilization is so poor among hospice patients, as well as methods to increase the patient and caregiver's satisfaction with the services they received.

Problem Statement

Respite services are under-utilized among hospice patients. Many patients fear being readmitted to a hospital, and as a result, family members are reluctant to use respite care. However, caregiver burnout is often reported in hospice family members and primary caregivers. Burnout has been identified as a chronic stress syndrome, and is mainly characterized by fatigue (Pfeffer et al., 2018). When caring for a family member enrolled in hospice, caregivers are often so preoccupied with caring for the patient that personal needs are neglected. Additionally, family members are faced with anticipatory grief while caring for the patient, who is often severely disabled and requiring significant assistance with activities of daily living, such as bathing, dressing, and toileting.

A study conducted by Yu et al. (2015) found that there was a positive correlation between caregiver burnout and the amount of care required by the caregiver. There are higher rates of caregiver burnout for patients that had severe disabilities and required more hours of care. Caregivers are often negligent of personal needs and emotions while caring for loved ones. Respite care allows the caregiver an opportunity to meet personal self-care needs and decrease stress levels, while ensuring their loved one is cared for.

Project Aim

The project attempts to determine if utilization of community-based respite care would decrease caregiver stress and improve overall satisfaction of hospice services. Additionally, the project aims to influence healthcare policy change in regard to Medicare's hospice guidelines. The goal is to ensure that patients and caregivers have respite care services available that meet the needs and expectations of the patient and caregiver, in an attempt to positively impact patients and family member perceptions on respite care services and increase utilization. This

project will survey caregivers of hospice patients to evaluate caregiver stress level and satisfaction with hospice services. The survey will evaluate the caregiver's satisfaction with hospice services, and whether the utilization of respite care positively affected the caregiver's stress level. The project will utilize surveys and an analysis of existing data to evaluate whether there is a correlation between use of respite care, lower stress levels, and higher satisfaction ratings on hospice surveys.

Clinical Question/PICOT

In terminally ill hospice patients, how does the use of community-based respite care, compared to patients who do not use respite care, affect the caregiver's overall satisfaction of hospice services and caregiver level of stress when patients live at home with a single primary caregiver? The population (P) is caregivers for adult patients enrolled in hospice services, who live at home with a single primary caregiver. The intervention (I) for this project is community-based respite care. The scholarly project will analyze the respite care program within Medicare's hospice benefit. Additionally, the project will compare (C) caregiver's stress levels for patients who do not use respite care to those patients who do utilize respite care services. The outcome (O) of the project is evaluating whether there is a reduction in reported level of stress for caregivers of patients who utilized respite services of hospice services, as well as an improvement overall satisfaction score. The goal of the project is to evaluate whether community-based respite care is more beneficial to hospice patients and families in reducing caregiver stress. Development of a respite care program that meets the needs of hospice patients should increase overall utilization of respite care services and decrease caregiver burnout. The project will focus on patients who live at home and have a single, primary caregiver during the last six months of life (T).

Congruence with Organization Structure Plan

The organization's focus is on providing patients with exceptional healthcare in their homes, whether it is a private home, assisted living, or skilled nursing, and to ensure the patient's comfort throughout their end of life journey. Hospice care focuses on maintaining the patient's quality of life, and also supporting the family members through the process. The organization identifies different care levels, to include respite, as a service available to ensure the focus remains on the patient's comfort and quality of life (Integrity Hospice Care, 2019). Additionally, the organization has contracted with facilities to provide respite care when caregivers need short-term relief from the intense responsibilities of caring for a loved one. While hospice agencies aim to ensure the patient's comfort and minimize caregiver strain, providers are only able to assist where the patient and family will allow. The goal of this project is to determine if broadening the utilization of respite services for hospice patients, will improve caregiver burnout, and increase overall caregiver satisfaction ratings.

Synthesis of Evidence: Search Strategy

The literature research was completed in several search engines, including Medscape, PLOS, Cochrane, PubMed, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) to evaluate evidence-based peer-reviewed articles. The keywords used in the search for literature on hospice respite care were "hospice services", "respite utilization", "hospice patient satisfaction", "hospice purpose", "caregiver burnout", and "community-based respite care". Results were limited to only include literature within the last 5 years. The search yielded over 5,000 research articles; however, the articles were narrowed down to focus on those involving hospice patients. Articles related to pediatrics were excluded from the literature review.

Synthesis of Evidence: Appraisal of Evidence

Utilization

Wang et al. (2015) found that use of hospice services varied among different regions in the United States. In 2011, only 47.6% of decedents used hospice services during the last six months of life. However, the percentages varied across the United States, with the lowest utilization being in Alaska at 20.3%. Another study conducted by Plotzke and Pozniak (2015) found that only 3% of patients enrolled in hospice during the last six months of life utilized respite services. More patients are electing to die at home due to better symptom management and overall satisfaction, when compared to deaths that occur in inpatient units (Lysaght & Ersek, 2013). The study is significant for evaluating how hospice services are used throughout the United States.

Hughes et al. (2019) conducted a systematic review to evaluate what patients and their families felt were most important about hospice services. Hospice is designed to provide patients comfort care during their end of life transition. One aspect identified in the study was the value of respite care. The study found that 85% of patients who utilized respite services had a positive experience and some caregivers did report a decrease in stress (Hughes et al.). The study also found that patients and caregivers valued the availability of hospice staff and services, and remaining comfort during their hospice journey.

Transitions During Hospice Enrollment

Wang, Aldridge, Gross et al. (2016) sought to evaluate care transitions during the last six months of a hospice patient's life. The study was aimed to determine why hospice patients have care transitions during the last six months and how these transitions impacted the patient and their family. Wang, Aldridge, Gross et al. considered transitions between hospices, hospitals,

skilled nursing facilities, and home health agencies. Wang, Aldridge, Canavan et al. (2016) analyzed whether continuous homecare reduced the amount of hospice patients who disenrolled or was hospitalized after starting hospice care. The study noted that continuous home care for symptom management improved the quality of care and decreased overall cost associated with end-of-life care. Additionally, caregivers of decedents were less likely to rate the care received as “excellent” for patients that died in an inpatient unit versus at home (Unroe et al., 2018). The study was significant in supporting continuous home care versus general inpatient care. Patients that were able to remain in a home setting for all of their hospice care had lower rates of hospitalization, and disenrollment from hospice services.

Community Based Respite Need

A study into respite care, conducted by Coelho et al. (2016), evaluated what comforts and discomforts patients associated with inpatient respite care. The study found that patients associated increased comfort with their environment and the level of knowledge attained by the individuals that were caring for them. The study was conducted on an inpatient palliative care unit. This provided beneficial information for this project because it further clarified hospice patients placed great emphasis on the environment in which they receive care. It is an important factor when analyzing their level of comfort.

Additionally, Vanderpitte et al. (2016) found that caregiver support was imperative in improving the overall health of informal caregivers. One form of support for caregivers is community-based respite services. Vanderpitte et al. indicated that informal caregivers had more health problems, social isolation, and higher episodes of depression. Providing support to caregivers was identified as an effective method to improve caregiver well-being and reduce

caregiver burden (Vanderpitte et al.). However, there was little research into the community-based respite services. More research needs to be completed to determine the benefits of respite.

A study conducted by Zarit et al. (2017) evaluated the validity of research into community-based services such as respite care. The authors found that quasi-experimental studies are comparable in validity to randomized control trials. While there are not many randomized control trials available for research into hospice respite care, other forms of research provide similar validity and can be utilized for research purposes.

Theoretical Framework

For the evaluation of satisfaction among hospice patients and their families, Kolcaba's Theory of Comfort provides the underlying framework to adequately guide this project. Kolcaba's Theory of Comfort, according to Coelho et al. (2016), focuses on meeting the needs of relief, ease, and transcendence. Kolcaba's theory aims to manipulate a patient's environment to enhance their comfort. Respite services provided to hospice patients should maintain the level of comfort expected by the patient and family when admitted to hospice care. Increased utilization of respite services is expected to decrease caregiver burnout, which further impacts the level of care and comfort the hospice patient receives. Kolcaba's theory is an appropriate approach for evaluating the clinical question in this project, as it allows you to assess patient's comfort and apply interventions to enhance comfort among hospice patients.

Chapter II: Methodology

Project Design

This project is a 2-part project that will evaluate the caregiver's level of stress as well as the caregiver's satisfaction with hospice services. Quality improvement studies use data to improve processes and outcomes in healthcare (Moran et al., 2020). This method of research is aimed at improving healthcare practices and influencing positive patient outcomes. The project will utilize a short survey that would be provided to caregivers of patients who are admitted to hospice and identified as living at home with a single primary caregiver. The survey will be used to analyze stress levels for caregivers of patients who have received respite care, as well as caregivers of patients who have not received respite care.

The second part of the project is a data analysis that will review existing data from the Centers for Medicare and Medicaid Services Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey. This part of the project will assess for differences in satisfaction scores between caregivers of patients who received respite services compared to scores of patients who did not receive respite care services during the hospice admission. The Medicare CAHPS data is the best way to assess satisfaction because the survey tool, Caregiver Self-Assessment Questionnaire, does not account for caregiver satisfaction with hospice services. Medicare CAHPS data provides a qualitative measurement of caregiver's experiences with hospice agencies. The survey asks specific questions regarding the caregiver's rating of the "hospice agency" and "willingness to recommend" (Centers for Medicare and Medicaid Services, 2019c). The data analyzed will be from Medicare CHAPS data obtained between October 1, 2016, and September 30, 2018, which is the most recent available data from the Centers for Medicare and Medicaid (Centers for Medicare and Medicaid, 2019_a).

Project Setting

The project is set to take place at Integrity Hospice in Gold Canyon, Arizona. Integrity Hospice is a community-based hospice agency with a patient census of 71 patients. The organization employs an interdisciplinary team, consisting of five nurse case managers and three social workers. The nurse case managers will assist with the project implementation. The interdisciplinary team will be educated on Medicare guidelines that govern the hospice respite program. In addition, the team will be educated on how to administer the tool in practice. Pending Institution Review Board approval, the tool will be implemented in January 2020, and will be utilized for all qualifying caregivers of hospice patients within the organization. The project is expected to run from January 2020 through March 2020.

Population

The project is aimed at assessing information obtained from caregivers of patients currently admitted to hospice services. The population includes caregivers for patients over the age of 65, all of whom have terminal diagnoses. The caregivers included in the study care for patients with diagnoses of Cancer, Late onset Alzheimer's disease, Heart Disease, Severe Protein-Calorie Malnutrition, and Pulmonary Disease. The patient population utilizing respite services are patients who live at home with a single primary caregiver. According to Centers for Medicare and Medicaid (2019b), approximately 99% of hospice patients were identified as receiving care at home during the hospice admission. The project will focus on the primary caregiver for the patient. The project will exclude caregivers of patients who reside in assisted living facilities, group homes, and skilled nursing facilities. The organization has a total census of 71 patients, however, only approximately 25 patients reside at home with a primary caregiver. Therefore, it is estimated that 25 caregivers will be eligible to participate. Participants will be

identified by the organization's nurse case managers and offered the opportunity to participate in the project. After obtaining verbal consent, the surveys will be given to caregivers of all qualifying patients admitted to Integrity Hospice at between January 2020 and March 2020. The nurse case manager will provide the survey to the caregiver, once verbal consent has been obtained. The survey completion will be done in one visit, there is no follow-up visits necessary. Completed surveys will be submitted to the project facilitator for data analysis.

The second part of the project will focus on Medicare CAHPS data obtained October 2016 to September 2018. This part of the project is designed to evaluate caregiver satisfaction with hospice services, as the survey tool does not measure satisfaction. Additionally, Medicare CAHPS data obtained between October 2016 through September 2018 is the most recent data available (Centers for Medicare and Medicaid, 2019a).

Tool

To evaluate the impact of respite care services on caregiver stress, the project will utilize the Caregiver Self-Assessment Questionnaire (Appendix A) developed and tested by the American Medical Association (American Psychological Association, 2019). Permission to utilize the tool was submitted to the Health in Aging Foundation (2020) and written approval was obtained (Appendix B). The survey is an 18-item self-reported tool used to analyze perceived stress levels for caregivers of patients diagnosed with chronic illnesses (American Psychological Association). The survey asks caregivers to provide "yes" or "no" responses to a series of 16 questions, such as "During the past week or so, I have felt completely overwhelmed" and "During the past week or so, I have felt strained between work and family responsibilities." (American Psychological Association). The remaining two questions ask caregivers to use the 10-point Likert scale to rate the caregiver's level of stress and current health.

The project will also use a data analysis of The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey, which is a Medicare initiative to evaluate hospice agencies based on customer feedback (Centers for Medicare and Medicaid, 2019_c). The CAHPS Hospice survey data will be utilized to evaluate satisfaction ratings for patients who received respite care services during the hospice admission, compared to patients who did not receive respite care services during the hospice admission. The main purpose for review of existing Medicare data is that the Caregiver Self-Assessment Tool does not measure patient or caregiver satisfaction with hospice services.

Project Plan

Implementation

The project will be completed in two phases to evaluate caregiver input. The first phase will take place early January 2020 and will consist of education for hospice staff members. Phase one will focus on educating the interdisciplinary team at Integrity Hospice regarding the current Center for Medicare and Medicaid guidelines for respite care utilization for hospice patients. The interdisciplinary team will consist of nurse case managers and social workers employed by Integrity Hospice. The staff will also be presented with the survey tool (Caregiver Self-Assessment Questionnaire) and educated on how to utilize the tool. Primary caregivers of patients who are admitted to Integrity Hospice on routine home care will be invited to complete the survey. The selection process will exclude caregivers for patients who do not reside in the home setting, such as patients whose primary residence is an assisted living, group home, or skilled nursing facility. Each participant will be given a four-digit unique identifier. To adequately identify caregivers of patients who have utilized respite care, the unique identifier will begin with the letter R. All other caregivers will have a four-digit unique identifier that

begins with the letter C. The other 3 digits in the unique identifier will be randomized numeric characters.

The second phase of the project will run from mid-January to late March. During the second phase, hospice nurse case managers will provide the survey to caregivers of all eligible hospice patients admitted to Integrity Hospice. The survey will look for differences, such as lower stress level scores, in the surveys completed by caregivers whose family member received respite services, compared to caregivers of patients who did not receive respite care.

Sustainability

The project is supported by the stakeholders involved in the initiative. Research has found that continued support of the scholarly project by the organization's stakeholders, and key decision-makers improves the projects ability to sustain over time (Moran et al., 2019).The leadership team at Integrity Hospice expressed the need for community-based respite care that meets the needs of the patient and the caregiver (F. Mwinyelle, personal communication, September 13, 2019).

Outcomes

The caregivers' responses will be analyzed to assess stress level. The expected outcome for this project is a reported lower level of stress in caregivers of patients who receive respite services during the hospice admission compared to caregivers of patients who do not receive respite services during the hospice admission. The data analysis of Medicare's CAHPS data will be interpreted to assess for higher caregiver satisfaction scores for patients who received respite services compared to patients who did not receive respite services. The project aspires to find a positive correlation between community-based respite care for hospice patients, and a decreased level of caregiver stress, as well as higher patient satisfaction scores. This project has the

potential to affirm the need for more community-based respite programs available to hospice patients. Given the poor utilization of respite services among hospice patients, this quality improvement project hopes to influence additional research into the cause of respite services poor utilization, and initiate change in the delivery of respite services to hospice patients.

Procedures for Data Collection

In order for data to be accurately analyzed, all caregivers participating in the project will receive the same survey. With permission from the survey owner (Appendix B), Health in Aging Foundation, the Caregiver Self-Assessment Questionnaire will be utilized throughout the implementation phase of the project. All nurse case managers will receive the same training regarding administration of the survey. Data from incomplete surveys will be excluded. Nurse case managers employed with Integrity Hospice will administer the survey to eligible caregivers. All surveys will be analyzed, and only data from completed surveys will be input into the database. No personally identifiable patient information will be obtained or input into the database.

Project Timeline

Upon approval, the project will begin January 2020. The educational portion of the project will be completed by mid-January 2020. Immediately following the nurse case managers education, the surveys will be provided to the caregivers and collected by the staff administering the surveys. Surveys will be completed from mid-January until March 1, 2020. Data analysis will occur from March 1, 2020 until April 1, 2020.

Data Analysis

Each survey participant will be issued a unique identifier in lieu of personally identifiable information, according to the previously indicated guidelines. The unique identifier will be

utilized to track the data, and distinguish data related to patients who received respite care from data related to patients who have not received respite care. The unique identifier will ensure that no patient information, such as name or medical record number, is obtained or transferred to the data analysis worksheet. The data will be entered into an excel spreadsheet and analyzed by the researcher, using Statistical Package for the Social Sciences (SPSS). The data will initially be input into an excel spreadsheet using the participant's unique identifier for tracking. Once the information is entered into the excel spreadsheet the original surveys will be discarded. The excel spreadsheet will be password protected, as an additional measure to maintain the integrity of the document. Once all data is collected it will be converted to SPSS version 26 for analysis.

Institutional Review Board and Ethical Issues

In order to maintain compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) throughout the process, each participant will be given a unique identifier. The Unique identifier will be a randomized four-digit number that will be used in lieu of patient or caregiver personally identifiable information. No personally identifiable information will be obtained or stored during the data collection process. Participants will be informed of the study, and provide verbal consent prior to completing the survey. The proposal was submitted to Bradley University's Committee on the Use of Human Subjects in Research (CUHSR) Institution Review Board in November 2019 for approval; approval was received January 2020 (Appendix E). The organization, Integrity Hospice, does not have an organized Institution Review Board. However, written permission to implement the project at Integrity Hospice has been obtained (Appendix D).

Chapter III: Organizational Assessment and Cost Effectiveness Analysis

Organizational Assessment

Readiness for Change

Executive leaders and staff employed at Integrity Hospice expressed positivity towards readiness for change within the organization and the respite care program. Executive leaders within the organization have expressed eagerness to assess the benefits of community-based respite care. Frank Mwinyelle, Chief Executive Officer, indicated that the topic of community-based respite care has been discussed among executive staff and members are anticipating the results of the research study (F. Mwinyelle, personal communication, September 13, 2019). As previously stated, recent studies found that only approximately 3% of hospice beneficiaries utilized respite care during the last six months of their life (Plotzke & Pozniak, 2015). Within the organization, the utilization of respite services is significantly lower. In 2019, 1.4% of hospice patients admitted to Integrity Hospice utilized respite services (F. Butler, personal communication, October 22, 2019). The respite care benefit is intended to provide up to five days of respite services to patients, in order to allow caregivers a break. The aim of this project is to determine if utilization of community-based respite care reduces caregiver strain and improves overall satisfaction with hospice services.

Barriers

Barriers related to the project include caregivers' willingness to participate. Given the organization's small patient census, reluctance to participate from the caregivers can limit the adequacy of the data obtained. Additionally, survey administrator knowledge regarding the survey tool is imperative. The reliability of the data can be negatively impacted by lack of knowledge and understanding related to the administration of the survey. To address this barrier,

all members of the interdisciplinary team will receive the same training and education regarding implementation of the project and survey tool.

Cost Effectiveness

The program will require minimal costs associated with the research and implementation (Appendix C). The educational material will be developed by the researcher, and presented to the interdisciplinary team during one of the scheduled bi-weekly interdisciplinary team meetings. The staff education and the survey administration will occur during employees' regularly scheduled work, and will not require additional healthcare provider time. The nurse case managers will assist with the implementation of the project by administering the Caregiver Self-Assessment Questionnaire to caregivers of eligible patients. The first portion of the implementation will consist of a 1-hour presentation for five nurse case managers at approximately \$35/hr, which will equal \$175. The administration of the survey tool will take approximately 10 minutes to complete, and will be administered to approximately 25 individuals. Administration of the survey tool will require approximately 250 minutes, or 4.16 hours, at \$35/hr which will equal \$145.00. The total estimated cost that will be absorbed by organization is \$320 in manpower hours. The budgeted cost for the survey printing is \$30. Additionally, licensing of the SPSS software will be purchased for a period of 12 months at a cost of \$90.99.

Chapter IV: Results

Analysis of Implementation Process

The implementation of the project was completed with minimal interruptions. The project received optimal support from all stakeholders involved, which included the project mentor, executive staff, nurses, and patient caregivers. The goal of the project was to determine if the use of community-based respite care reduced the level of caregiver stress, and improve overall satisfaction with care received for patients admitted to hospice and living at home with a single, primary caregiver. The project utilized a survey tool to assess the caregivers' level of stress; The results from caregivers of patients who received respite services were compared to the scores received from caregivers of patients who did not receive respite services.

The implementation process was multi-faceted, and began with an educational presentation for stakeholders within the organization. Information regarding the clinical questions, problem background, survey tool, and collection process was provided to stakeholders. Additionally, a questions and answers segment was included to ensure all members on the team had a thorough understanding of the information received. The survey tool was administered to eligible caregivers, after obtaining verbal consent to participate. The surveys were administered February 2020 through April 2020.

As completed surveys were returned to the project manager, survey scores were transferred to a password-protected spreadsheet, where the information was analyzed for trends. Throughout the implementation process, the project manager conducted meetings with the stakeholders to ensure the project timeline remained on course, and to evaluate and resolve any obstacles presented during the implementation process. According to Terry (2015), data analysis

for quality improvement projects are considered an ongoing process, as the project manager must continually evaluate the information received.

Analysis of Project Outcome Data

During the planning process, the DNP student identified 25 eligible participants within the organization. Of the 25 participants that were identified, 18 participants completed the survey tool and were included in the data analysis. The 18 participants included four caregivers of patients who received respite care services, and 14 caregivers of patients who did not receive respite care services. The survey tool identified participants as experiencing a high level of stress if:

- The answer to question 4 or 11 was “yes”
- The total score for “yes” answers = 10 or more
- The score for questions 17 or 18 = 6 or higher

Based on the above criteria, a total of 11 participants were identified as having a high degree of stress. Furthermore, of those 11 participants, ten were caregivers of patients who have not received respite care services, and one was the caregiver of a patient who did receive respite care services.

Figure 1 SPSS version 26 exposure*outcome Crosstabulation

exposure * outcome Crosstabulation					
		outcome			
			high risk	low risk	Total
exposure	respite	Count	1	3	4
	% within exposure		25.0%	75.0%	100.0%
	non respite	Count	10	4	14
	% within exposure		71.4%	28.6%	100.0%
Total		Count	11	7	18
		% within exposure	61.1%	38.9%	100.0%

Risk Estimate			
	Value	95% Confidence Interval	
		Lower	Upper
Odds Ratio for exposure (respite / non respite)	.133	.010	1.696
For cohort outcome = high risk	.350	.062	1.973
For cohort outcome = low risk	2.625	.963	7.157
N of Valid Cases	18		

The crosstabulation conducted in SPSS version 26 indicated that caregivers of patients who did not receive respite care services were 35 times more likely to experience high levels of stress.

The second part of the project was an analysis of Medicare CAHPS Hospice survey data to analyze for differences in the score results among these two groups. The data report for Medicare's most recent reports were reviewed, however, there was no specification in whether the decedent received respite care services during the last six months of life. Based on this information, the project was unable to determine if there was a correlation in caregivers' satisfaction scores on Medicare's CAHPS hospice surveys in relation to use of respite services.

Chapter V: Discussion

Findings

The project evaluated the survey responses for 18 eligible participants utilizing the Caregiver Self-Assessment Questionnaire, which was created by the American Medical Association (American Psychological Association, 2019). The survey results identified one of the four caregivers for patients who have received respite services as having a high level of stress. This was equivalent to 25% of the caregivers in this category as having a high level of stress. The survey results identified 10 of the 14 caregivers of patients who have not received respite services as having a high level of stress. This was equivalent to 71% of caregivers in this category as having a high level of stress. This reflected a difference in the perceived stress levels among these two groups. The results indicated the use of community-based respite services may be beneficial in reducing caregiver stress. The project was unable to determine if there was a relationship between caregiver satisfaction scores, and the use of respite services based on hospice CAHPS data.

Limitations or Deviations from Project Plan

During the implementation and data evaluation process there were multiple project limitations that were identified. Project limitations included small sample size, lack of specification for a time-frame related to respite care usage in relation to survey completion, and reliance on nursing case managers to return the surveys within a timely manner. The organization had a small patient census, and as a result the number of eligible participants was limited. This project could have had a larger sample if it was conducted within a large organization or across multiple organizations within the specialty. The project also did not specify a timeframe related to the use of respite care. The project included survey results for

caregivers of patients who utilized respite services in the months immediately preceding the survey, as well as those who received respite services more than three months prior to the survey completion. This project could have yielded more accurate results if the survey tool was administered over a longer period of time, and if the survey was completed by caregivers within the weeks immediately following the use of respite services. Additionally, the project utilized multiple nurse case managers within the organization to administer the survey tool to eligible caregivers during the course of their normal workday. Of note, the nurse case managers initially met with caregivers weekly, however, The Community Health Accreditation Partner, CHAPS, guidelines changed the frequency of nurse visits in response to the COVID-19 national pandemic. As a result, the surveys were not completed on schedule, and surveys were not immediately returned to the DNP project manager. Lastly, the project did not have access to Medicare's Hospice CAHPS scores. As a result, the project did not identify any relationship between respite services and an increase in Medicare's Hospice CAHPS scores.

Implications

The project had many implications for practice within the hospice field. The results of the project did indicate that 25% of caregivers with patients receiving respite services experienced high stress and 71% of caregivers with patients not receiving respite services experienced high stress. The project results suggest the need for community-based respite services to be available for patients receiving hospice services. Additionally, hospice policy-makers are urged to consider methods to increase availability and utilization of community-based respite services among patients admitted to hospice services.

Future research should focus on analyzing the benefits of community-based respite services among hospice populations. Researchers are urged to conduct quantitative studies over

an extended-period of time, that would provide a better indication of the relationship between community-based respite and reduced caregiver stress levels. Additionally, an analysis of caregiver stress before and after respite care use may provide clearer indications on community-based respite's benefits in reducing caregiver stress.

Hospice nurse case managers must become educated on the use and benefits of community-based respite services for both the patients and the caregivers. Nurses should be able to identify patients and caregivers that can benefit from the use of respite services and be prepared to provide education and care coordination for patients and caregivers in need. As nurses become more aware of the need for community-based respite care among hospice patients, nurses can assume an active role in the advocating and lobbying for policy changes which would improve access to services for individuals within the focus population, as well as other high-risk populations.

Chapter VI: Conclusion

Value of the Project

The DNP project results indicated that community-based respite care can be beneficial for hospice patients and caregivers of terminally-ill patients. While additional research must be completed, caregivers of hospice patients who received respite care services indicated lower overall scores on the Caregiver Self-Assessment Questionnaire. Currently approximately 4% of hospice patients within the United States utilized respite care benefits during the last six months of life. The project was significant in showing that hospice service providers, along with policymakers, must investigate measure to increase utilization of community-based respite care among hospice patients. As a result of the project, the executive staff at Integrity Hospice is presented with information showing the importance and value of community-based respite services, and the organization can further evaluate methods to improve utilization among patients admitted to Integrity Hospice.

DNP Essentials

According to the American Association of Colleges of Nursing (AACN) (2006), the *DNP Essentials* are identified as eight core competencies that form the foundation of Advance Practice Nursing. All DNP-prepared Advance Practice Nurses (APNs) should exhibit competency in each of the *DNP Essentials*. This scholarly project incorporated each of the *DNP Essentials* during the planning, implementation, and evaluation processes. However, the following three *DNP Essentials* were particularly related to the goals and outcomes of the scholarly project.

Essential II: Organizational and Systems Leadership for Quality Improvement and Systems Thinking This *DNP Essential* focuses on the APNs' role in advancing quality improvement within healthcare organizations. According to AACN, (2006), DNP-prepared

APNs are in a unique position to influence patient outcomes through direct patient care, evaluation of population needs, and influence over organizational change. *Community-Based Respite Care* is a quality-improvement directed scholarly project. The project worked within *DNP Essential II* to assess the needs of the target population and identify areas for improvement.

Essential V: Health Care Policy for Advocacy in Health Care The project also worked heavily within *DNP Essential V* in regards to the project's aim to influence policy change regarding community-based respite. The AACN (2006) identified that DNP-prepared APNs need to possess competency in this essential due to the importance of policy development and influencing policy change within healthcare systems. This project utilized data collected to reflect the need for policy changes that can increase access to community-based respite services for hospice patients. Currently, the CMS guidelines require respite care services are provided in a Medicare approved facility such as hospitals, inpatient hospices, and skilled nursing facilities (CMS, 2019a). As a hospice nurse case manager, I have experienced some difficulty in finding facilities that are Medicare approved, contracted with the hospice, and with open-beds for a hospice respite patient. My recommendation would be to influence policy changes that would allow state-approved facilities, such as senior care group homes, to be approved as respite care providers. According to AACN (2006), *DNP Essential V* provides DNP graduates with the skills and knowledge to advocate in these arenas specific to health care systems.

Essential VI: Interprofessional Collaboration for Improving Patient and Population Health Outcomes Another major aspect of the planning, implementation, and evaluation of this project was interprofessional collaboration, which falls within *DNP Essential VI*. This Essential was identified by AACN as a cornerstone for Advance Practice Nursing, and provides DNP-graduates with a high level of proficiency and ability to function as leaders within collaborative

teams (AACN, 2006). This project required collaboration between the DNP-student and multiple members of the interdisciplinary team, as well as the specialist in Information Technology.

Within DNP practice, interprofessional collaboration is imperative to ensure positive patient outcomes by facilitating high functioning teams and guiding patient-centered care.

Plan for Dissemination

This scholarly project will be presented to the DNP project team members during an oral presentation via live video. The presentation will also be open to all members of Bradley University's faculty, students, administration, community members, as well as the DNP students, family, and friends. The project will also be submitted to the Doctor of Nursing Practice Doctoral Project Repository. Lastly, printed, bound-copies will be presented to members of the project team who request to have one prepared.

Attainment of Personal and Professional Goals

The main goal of the project was to identify whether community-based respite care would help reduce caregiver stress among the hospice patient population. The project also aimed to determine if reduction in caregiver stress through use of community-based respite care services would positively impact caregiver satisfaction levels with hospice services. The project identified some limitations during the implementation, and data evaluation process, however, the overall outcome suggests that this topic should be further investigated. Additional research should be conducted to analyze the value of community-based respite care and identify measures that can be taken to improve utilization rates among hospice patients.

Overall, the project provided insight into the need for community-based respite services as well as its effect on caregiver stress. Personally, the project provided additional skills needed to continue to navigate the role of an Advanced Practice Nurse, and advocate for change within

healthcare systems. This scholarly project improved overall competency in the *DNP Essentials*, which provides the foundation for Advanced Nursing Practice.

Conclusion

Community-based respite care has been an underutilized benefit among hospice patients. However, caregiver stress and caregiver strain remain an issue. The Centers for Medicare and Medicaid Services (2019_a) identified respite care benefits as a means to provide relief for caregivers. The project aimed to determine if the use of community-based respite care among hospice patients, compared to patients who do not use respite care, had any effect on the caregiver's overall satisfaction of hospice services and caregiver level of stress when patients live at home with a single primary caregiver. The results of the project indicated that community-based respite care was beneficial in reducing caregiver stress, however, the project was not able to identify any direct correlation between Medicare's Hospice CAHPS scores and the use of community-based respite services. This is definitely an area that requires additional research.

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Appendix A

Caregiver Self-Assessment Survey

ID # _____

Caregiver Self-Assessment Questionnaire**How are YOU?**

Caregivers are often so concerned with caring for the relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have ...

- | | | | |
|----------------------------------------------------------------------------------|----------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------|
| 1. Had trouble keeping my mind on what I was doing.... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 13. Had back pain..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 2. Felt that I couldn't leave my relative alone..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 14. Felt ill (headaches, stomach problems or common cold)..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 3. Had difficulty making decisions..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 15. Been satisfied with the support my family has given me..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 4. Felt completely overwhelmed..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 16. Found my relative's living situation to be inconvenient or a barrier to care..... | <input type="checkbox"/> Yes <input type="checkbox"/> No |
| 5. Felt useful and needed | <input type="checkbox"/> Yes <input type="checkbox"/> No | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____ | |
| 6. Felt lonely..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____ | |
| 7. Been upset that my relative has changed so much from his/her former self..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 8. Felt a loss of privacy and/or personal time..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 9. Been edgy or irritable..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 10. Had sleep disturbed because of caring for my relative..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 11. Had a crying spell(s)..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |
| 12. Felt strained between work and family responsibilities... | <input type="checkbox"/> Yes <input type="checkbox"/> No | | |

Comments:

(Please feel free to comment or provide feedback.)

Self-Evaluation

To determine the score:

1. Reverse score questions 5 and 15.
For example, a "No" response should be counted as a "Yes" and a "Yes" response should be counted as a "No."
2. Total the number of "yes" responses.

To interpret the score

Chances are that you are experiencing a high degree of distress if any of the below is true:

- If you answered "Yes" to either or both questions 4 and 11
- If your total "Yes" scores = 10 or more
- If your score on question 17 is 6 or higher
- If your score on question 18 is 6 or higher

Next Steps

- Consider seeing a doctor for a check-up for yourself
- Consider having some relief from caregiving (Discuss with your healthcare provider or a social worker the resources available in your community.)
- Consider joining a support group

Valuable resources for caregivers

HealthinAging.org
(800) 563-4916 | www.healthinaging.org

Caregiver Action Network
(202) 454-3970 | www.caregiveraction.org

Eldercare Locator
(a national directory of community services)
(800) 677-1116 | www.eldercare.gov

Family Caregiver Alliance
(800) 445-8106 | www.caregiver.org

Medicare Hotline
(800) 633-4227 | www.medicare.gov

National Alliance for Caregiving
(301) 718-8444 | www.caregiving.org

AGS/HIAF 7.24.2014

This questionnaire was originally developed and tested by the American Medical Association.
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For permission, contact info@healthinaging.org.

Appendix B

Caregiver Self-Assessment Tool Permission



THE OFFICIAL
FOUNDATION OF THE
AMERICAN GERIATRICS SOCIETY

40 FULTON STREET, 18TH FLOOR
NEW YORK, NEW YORK 10038
212.308.1414 T
800.563.4916 T
Healthinagingfoundation.org

November 7, 2019

Octavia Garcia, BSN, RN
7113 W. Sophie Ln
Laveen AZ 85339
619-600-9353
ogarcia@mail.bradley.edu

Dear Octavia Garcia,

Thank you for your interest in HealthinAging.org, and for your inquiry about the "[Caregiver Self-Assessment Questionnaire](#)" (2015) tip sheet, for use in the following way:

- Inclusion in Appendix of DNP Project titled "Community-Based Respite care."
- The questionnaire will be distributed to caregivers of patients admitted to Integrity Hospice, LLC in Gold Canyon, Arizona between Jan. 2020 – Mar. 2020. The questionnaire will be used to analyze stress levels of caregivers for patients that have received respite care services, compared to caregivers of patients who have not received respite care services. The project is aimed at determining if community-based respite care decreases caregiver stress levels for patients admitted to hospice.

Permission is granted for the above provided that:

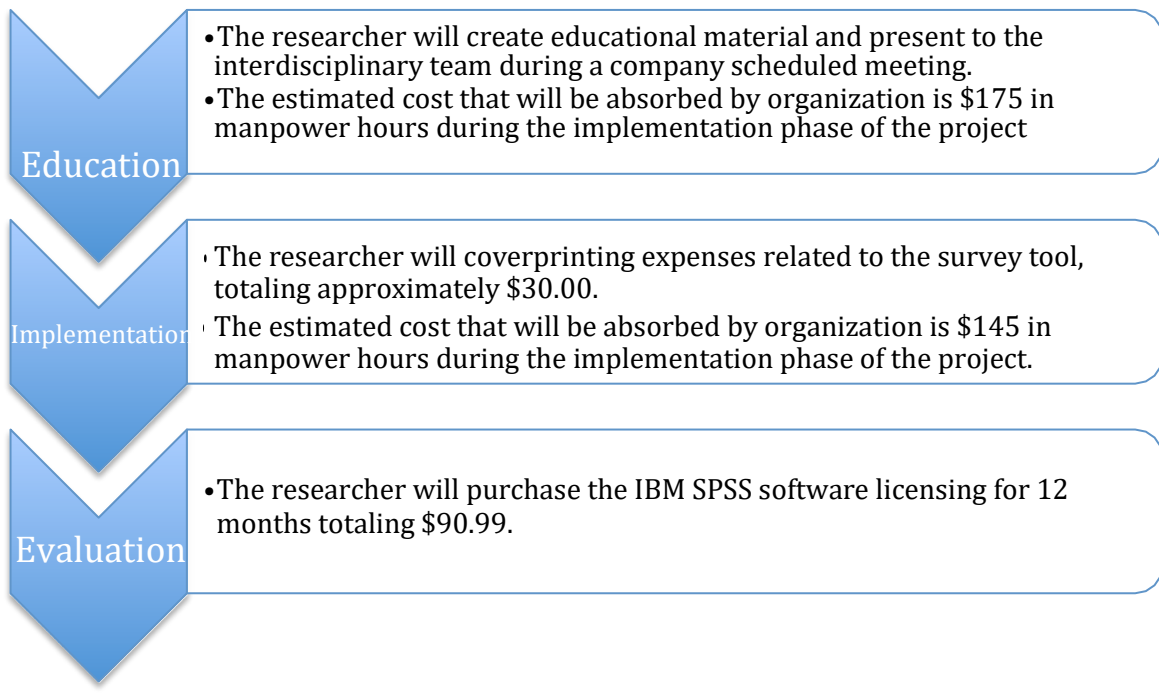
1. Permission to reprint and distribute the "Caregiver Self-Assessment Questionnaire" (2015) tip sheet, is limited to use in the above stated manner only. Rights **do not** apply to revised editions. Edits or translations to the material are **not** allowed. Rights apply to print/hardcopy and/or password protected web-platform only; other open-access website electronic rights **do not** apply. **In the event of publishing study, please contact for further permission.**
2. The Society does NOT endorse companies, products or services, and strictly prohibits any suggestion of endorsement, recommendation, or superiority of one company, product or service over another company, product or service.

If you've any further questions, please feel free to contact me at egallagher@americangeriatrics.org.

Sincerely,
Elisha Medina-Gallagher
Manager, Special Projects
American Geriatrics Society


Appendix C

Project Budget



Appendix D

Written Approval to Conduct Project at Integrity Hospice Care.

 <p>INTEGRITY HOSPICE CARE <small>CARING. COMFORT. FAMILY.</small></p>	<p>6877 S. Kings Ranch Road Suite 1 Gold Canyon, AZ. 85118</p>	<p>Office - 480-426-0255 Fax - 480-499-5859 Toll Free - 855-760-4212 www.integrityhospiceaz.com</p>
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November 27, 2019

To whom it may concern

This letter is to acknowledge that Integrity Hospice Care does not have its own institution review board (IRB), and that Octavia Garcia has permission to complete her project "Community-based Respite Care" at Integrity Hospice Care.

If you have any questions please feel free to reach out to me.

Sincerely,



Farah Butler
Administrator
Integrity Hospice Care
6877 S Kings Ranch Rd, Ste1
Gold Canyon, AZ 85118
Ph:480-426-0255

Appendix E

IRB Approval



DATE: 7 JAN 2020

TO: Octavia Garcia, Maureen Herman
FROM: Bradley University Committee on the Use of Human Subjects in Research

STUDY TITLE: Community-Based Respite Care
CUHSR #: 93-19
SUBMISSION TYPE: Initial Review

ACTION: Approved
APPROVAL DATE: 7 JAN 2020
REVIEW TYPE: Quality Assurance

Thank you for the opportunity to review the above referenced proposal. The Bradley University Committee on the Use of Human Subject in Research has determined the proposal to be NOT HUMAN SUBJECTS RESEARCH thus exempt from IRB review according to federal regulations.

The study has been found to be not human subject research pursuant to 45 CFR 46.102(i), not meeting the federal definition of research (not contributing to generalizable knowledge). Please note that it is unlawful to refer to your study as research.

Your study does meet general ethical requirements for human subject studies as follows:

1. Ethics training of project personal is documented.
2. The project involves no more than minimal risk and does not involve vulnerable population.
3. There is a consent process that:
 - Discloses the procedures
 - Discloses that participation is voluntary
 - Allows participants to withdraw
 - Discloses the name and contact information of the investigator
 - Provides a statement of agreement
4. Adequate provisions are made for the maintenance of privacy and protection of data.

Please submit a final status report when the study is completed. A form can be found on our website at <https://www.bradley.edu/academic/cio/osp/studies/cuhsr/forms/>. Please retain study records for three years from the conclusion of your study. Be aware that some professional standards may require the retention of records for longer than three years. If this study is regulated by the HIPAA privacy rule, retain the research records for at least 6 years.

Be aware that any future changes to the protocol must first be approved by the Committee on the Use of Human Subjects in Research (CUHSR) prior to implementation and that substantial changes may result in the need for further review. These changes include the addition of study personnel. Please submit a Request for Minor Modification of a Current Protocol form found at the CUHSR website at <https://www.bradley.edu/academic/cio/osp/studies/cuhsr/forms/> should a need for a change arise. A list of the types of modifications can be found on this form.

While no untoward effects are anticipated, should they arise, please report any untoward effects to CUHSR immediately.

This email will serve as your written notice that the study is approved unless a more formal letter is needed. You can request a formal letter from the CUHSR secretary in the Office of Sponsored Programs.