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Policies and Procedures to Address Respite Care

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This is to certify that the doctoral study by

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has been found to be complete and satisfactory in all respects,
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Abstract

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BSN, University of South Carolina Aiken, 2006

Project Submitted in Partial Fulfillment

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Abstract

Hospice services are utilized by more than 1.6 million people yearly, and there are a great number of caregivers who are tasked with caring for these individuals at home. Caregivers are at risk for fatigue, burnout, and decline in their own physical and mental health. While the Centers for Medicare and Medicaid Services (CMS) cover costs of temporary respite care for hospice patients, the caregivers' needs for respite care are often unrecognized and unaddressed. The purpose of this project was to plan a respite program within the hospice agency consisting of revised respite policy and procedures, the Caregiver Reaction Assessment (CRA) tool to routinely assess the caregiver for burnout and/or fatigue, and a detailed outline for the implementation of respite care. Anderson's behavioral model of service was used to guide the project's understanding of the underutilization of respite services. This project was guided by the practice-focused question examining the development of an evidence based caregiver respite program within the hospice agency. The program was developed based on a review of peer reviewed research studies and the input of a project team of local experts. The project team participated in the project that created a respite policy which includes a biweekly caregiver assessment and step-by-step directions on how to implement respite care. A final report was developed and submitted to the Hospice agency. This revised policy and procedure includes a blueprint for implementation and a full set of recommendations on the process, use of the CRA, educational in-services, and evaluative methods. These recommendations have the potential for positive social change by increasing patient and caregiver outcomes, serving as an example for other hospice agencies to follow, and improving care at the end of life.

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Dedication

  I would like to dedicate this project to my children who have been my light and driving force in life, to my husband, my sister, and my parents for their love, dedication, support, and encouragement. I would also like to acknowledge my co-workers at both the college and the hospice agency for all of their support and well wishes. Halcyon, thanks for all of your help with this project. Lastly, thanks to all of my friends and church members who always supported me, and offered their prayers and encouraging words.

  Thank you all!

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Section 1: Introduction

Introduction

Caregivers of terminally ill patients are often faced with significant burdens and stressors due to their newly defined roles and responsibilities. They carry the burden of providing supportive, financial, physical, and emotional care to their dying loved one while maintaining their personal lives, caring for other family members, and performing various other individual and professional duties. All of these factors are coupled with the anticipated death of their dying loved one. Due to these stressors, caregivers often face burnout and/or compassion fatigue. Caregiver burnout and/or compassion fatigue is defined as physical exhaustion including a negative self-concept, negative job attitude, and loss of concern and feeling for patients (Keidel, 2002). When reaching burnout or compassion fatigue, the caregiver has become overwhelmed with the daily care of their dying loved-one and may begin to exhibit physical exhaustion, financial strain, and/or emotional dismay.

Respite care is designed to provide temporary relief to the caregiver by relieving them of their duties for a designated period of time. This resource is arranged through the hospice agency that is providing palliative care for the patient by supplying temporary care through the use of in-patient facilities where the patient can be admitted for stay without terminating their hospice agreement. Respite care allows the caregiver time to rest and recuperate, take vacations, handle personal needs, and care for their family. Unfortunately, caregiver burnout and/or compassion fatigue is not always assessed or identified on a regular basis, and the needed help is not offered to the caregiver at the appropriate time. Failure to assess or identify caregiver burnout and/or fatigue is due to

the fact that no regulatory standards are in place that require hospice agencies to perform

routine caregiver assessments to identify the caregiver's needs. In a survey of 2,066

people serviced by hospice, only 7% used respite care (Carlson, Morrison, Holford, &

Bradley, 2007), thereby, underusing a precious resource that could enhance the quality of

care delivered to the dying patient by preventing caregiver strain and exhaustion. When

caregivers exhibit burnout or fatigue, the stress and sense of being overwhelmed can alter

the level or quality of care provided to the dying patient due to the caregiver's enhanced

stress levels, physical and mental deterioration, sense of resentment, and guilt. Adequate

identification of need and the provision of respite care can help relieve the caregiver and

allow adequate rest and recuperation. Proper identification and respite care

implementation results in a higher quality of care administered to the dying patient while

avoiding both mental and physical stressors that can affect the well-being of the

caregiver. In Section 1, I identify the problem and purpose statements, and I discuss the

nature of the doctoral project and its significance.

Problem Statement

The additional stress and responsibilities experienced by the caregiver can have

both physical and mental effects as they may begin to experience a decline in health,

feelings of fatigue, and frustration. These feelings leave them disabled and unable to

provide adequate care to their loved one. Currently, no formal assessment tools or

policies are used within the hospice agency to assess or identify the needs of the

caregiver. This is due, in part, to the lack of established regulations by the Centers for

Medicare and Medicaid Services (CMS) for identifying caregiver stress and/or burnout.

Regarding respite care, the CMS does not provide regulation on how or when to identify

the need for respite care, and it does not regulate the frequency of identifying the need for respite care. The CMS provides regulations on only reimbursement for respite services, the types of facilities in which respite care can occur, and the length of time which a person can remain under respite care. According to the *CMS Medicare Benefit Policy Manual*, Chapter 9, Section 40.2.2, published in 2015 (Appendix A):

> Respite care may only be provided in a Medicare participating hospital or hospice inpatient facility, or a Medicare or Medicaid participating nursing facility. Respite care may be provided only on an occasional basis and may not be reimbursed for more than 5 consecutive days at a time.

Strained caregivers who remain without support are at risk of burnout, which leads potentially to the "double boomerang" effect of one patient receiving informal care eventually leading to two patients dependent on formal care (van Exel, de Graaf, & Brouwer, 2008). Many caregivers fail to realize the need for assistance until they begin to physically decline, deteriorate, and experience signs and symptoms of disease and/or problems. Therefore, it was imperative that the hospice agency developed a system that allowed the nurses to routinely assess and identify the needs of the caregiver and perform the appropriate interventions to prevent compassion fatigue and burnout. This was done through the adoption, development, and use of assessment tools, policies, and procedures within the hospice agency. I led this project with the guiding practice focus question: How can an evidence based caregiver respite program be established within the hospice agency?

Purpose Statement

To prevent caregiver burnout and/or fatigue, the hospice agency must address the situation in advance. Hence, the purpose of this project was to plan a caregiver respite program within the hospice agency that includes policies and procedures directing the assessment of the caregiver, determine when to implement respite care, and outline the respite implementation procedure. The overall goal of the respite program consists of the prevention of caregiver burnout and fatigue. The project objectives consist of: (a) setting out a description of the need for respite services, (b) the adoption of a caregiver assessment tool, (c) the creation of policies and procedures that will direct a routine caregiver assessment, and (d) outlining the respite implementation process.

Nature of the Doctoral Project

For the purpose of this project, I have conducted a search for literature using the Walden Library. I selected the following electronic databases: CINAHL, Medline, ProQuest Nursing and Allied Health Source, EBSCO and Ovid Nursing Journals. I used articles within 15 years of publication, and the key terms included *caregivers*, *carer*, *respite care*, *palliative care*, *hospice*, *support*, *Medicare*, *policies*, *burnout*, and *compassion fatigue*. Additional sources of evidence included the use of national sites such as the National Hospice and Palliative Care Organization (NHPCO) and the Centers for Medicare and Medicaid Services (CMS). These sites included information on hospice practices, rules, and regulations. I organized and analyzed the data that I retrieved. The categories I created include the following: caregiver fatigue and burnout, caregiver assessment tools and their use, implementation and use of respite care, and policies and procedures related to respite care. The findings from the acquired resources assisted in

creating a set of policies and procedures that are designed to formally and routinely assess and identify the need of caregiver assistance and/or respite care along with the provision of a structured plan for respite care implementation.

Significance

The hospice industry has experienced significant growth as more people are deciding to die at home with their family and personal items near. To meet this need, there has been a 125% increase of newly formed hospice agencies in the United States since the year 1992 (Carlson et al., 2007). Also increasing is the number of family members caring for their dying loved ones at home, who are at risk of experiencing burnout and fatigue and are in need of respite services. These caregivers, and their dying loved ones, are major stakeholders of this project because they are the ones who are at risk of experiencing mental and/or physical breakdown due to the added burden of caring for a dying loved one and experiencing the need for respite care. Other stakeholders consist of the hospice agency nurses, social workers, chaplains, the medical director, and administration. The nurses are responsible for assessing the situation and determining a need, documenting, initiating the respite care process, and preparing the patient and the family for respite care. The social worker begins the process by contacting possible facilities, arranging for care, and coordinating all efforts. Chaplains are resources who can, or will, identify the need for respite services upon their visits and pass this information onto the nurse and social worker for follow-up. Other stakeholders consist of the agency's medical director and other administrative staff who approve respite care, secure new and maintain current contracts with respite agencies, and arrange payment for respite services.

As stated previously, no nationally set guidelines or polices exist related to the process or frequency of a caregiver assessment, what constitutes the need for respite care, or how the respite process is implemented by the hospice agency. The only guidelines provided by the CMS are the type of facility used for respite care and the length of stay per respite event. Due to this fact, this project contributes to the hospice nursing practice by establishing routine guidelines and processes to identify the caregiver's needs through the adoption and routine use of a caregiver assessment tool and the provision of explicit instructions that guides the implementation process of respite care by the hospice agency. The policy and subsequent provision of appropriate respite resources will help provide relief to the caregiver, lower their risk of physical and mental breakdown, and increase the level of care provided to the dying patient by the caregiver. These policies and procedures can serve as a foundation or guideline for other hospice agencies to adopt and/or create their own caregiver assessment tools, develop their own policies and procedures that will direct the use of said caregiver assessment tools in the identification of the need for respite care, and/or enhance their respite implementation process. This project can also be used to establish a need for such a tool or guidelines on a national level.

Last, this project can project positive social change by enhancing patient outcomes and the caregiver's level of satisfaction. For example, it may be the wish of the dying client to expire peacefully at home but, due to the caregiver's stress and sense of being overwhelmed, they may call 911 and admit the patient into the hospital. If the caregiver is provided with temporary relief, they are allowed time to recuperate and decrease their levels of stress resulting in an increased level of satisfaction so that they

are not burdened and overwhelmed. Caregiver respite could result in maintaining the dying patient's wishes to expire at home.

Summary

Due to the increased responsibilities to care for the dying patient at home, caregivers are at risk of experiencing caregiver burnout and compassion fatigue that could, in return, negatively affect their health. Assisting the caregiver in preventing fatigue and caregiver burnout may include establishing policies and procedures that will guide a routine caregiver assessment, identifying the need for, and guiding the implementation process of respite care. This project created policies and procedures that will guide a routine caregiver assessment through the use of an adopted caregiver assessment tool, determine a need for respite care, and provide specific guidelines on the process of respite care implementation.

Section 2: Background and Context

Introduction

The emotional and physical strain experienced while providing care to an ill family member can burden the most competent caregiver. This is especially true for caregivers of hospice patients, as they face the dual challenges of providing physical and emotional care for their loved one while also coping with the anticipated death (Empeño et al., 2011). Currently, the problem within hospice care consists of the need to identify and address the needs of the caregiver to prevent caregiver fatigue and burnout. Therefore, the purpose of this project was to plan a caregiver respite program within the hospice agency that includes policies and procedures that direct the assessment of the caregiver, determine when to implement respite care, and outline the respite implementation procedure. I guided my work with the following focus question: How can an evidence based caregiver respite program be established within the hospice agency? In Section 2, I discuss the concepts and theories that informed the project, the relevance to nursing practice, local background and context of the practice problem, the role of the DNP student, and role of the project team.

Concepts, Models, and Theories

The model that I used to guide this project was that of the Andersen Behavioral Model of Service Use. Andersen's behavioral model has been used extensively in studies investigating the use of health services (Babitsch, Gohl, & Lengerke, 2012). This model was helpful in explaining the use of various health services and why families use or disuse these services, and it aided in developing polices designed to promote access to health care services. Andersen's model is composed of the following three factors:

1. *Predisposing factors.* These factors consist of the characteristics of a person's age, race, and personal health beliefs. It also consists of the social components of educational background and/or level, occupation, familial roles and position, and ethnicity.

2. *Enabling factors.* These factors consist of familial support, financial means and personal finances and/or wealth, insurance accessibility, and community resources. This component also consists of organizational factors that include the person's normal (or regular) health care source, the available transportation to health care, the time it takes to travel there, and the time the person spent waiting in the doctor's office.

3. *Need factors.* These factors are both perceived and actual (or evaluated). The perceived need factors are defined as what the client see their needs as being. This includes their perceptions of their health status, functional state, or signs and symptoms of disease. The other need factor is that of the actual, or evaluated need. This is what the health care provider determined as the client's needs. This is done through a professional assessment that will identify the need for medical care and/or the client's measured health status based on the established criteria.

All of these factors play a significant part in determining whether a person will use health and social services. Within the hospice setting, these factors are used to help determine if the caregiver could benefit from respite care and the associated reasons for not using these services. For example, when using Anderson's model in determining the need of respite care, the agency would examine the caregiver's attitude and beliefs toward the use of respite care, the caregiver's role within the family and their support

system, and if their educational level plays a part in the decision. Other potential

components are the availability of respite care, location of the long-term care facilities in

which caregivers will be residing for respite care, transportation used to get there, and

any other associating factors related to the client's transition to respite care. Last, the

caregiver's perception of the need for respite versus the actual nursing assessment that

determined the need is analyzed to satisfy the need factor.

Relevance to Nursing Practice

Hospice was developed in the early 1960s to address the multidimensional needs

of patients suffering from advanced illness and their families. These needs were not being

met by the medical system and, as a result, the hospice industry has experienced dramatic

growth and change in time (Carlson, Morrison, Holford, & Bradley, 2007). The increase

of hospice agency development has led to a major increase in Medicare spending to fund

this growth. Medicare spending under the Medicare Hospice Benefit increased from $445

million in 1991 to $3.6 billion in 2001 (CMS, 2005), and the number of Medicare hospice

beneficiaries increased more than six-fold during the same period (CMS, 2005). This

dramatic growth signifies an increase in the number of hospice patients and the

caregivers tasked with their care, thus increasing the risk of caregiver strain and burnout.

Because the anticipated need for caregivers is expected to grow, a critical need exists to

define and implement interventions that reduce caregiver strain and burden (Honea et al,

2008).

Respite care is considered a key support service for caregivers, with the ascribed

benefits including lower carer strain, and advantages for the care-recipient including

delayed institutionalization (Pinquart & Sorensen, 2006). Respite care allows the

caregivers the ability to receive a break, and when this is done they feel less hostile to the care recipient, use less negative coping strategies (Parker, Mills, & Abbey, 2008; Mason, Weatherly, Spilsbury, Golder, Arksey, Adamson, & Drummond, 2007), and are more reluctant to hospitalize or institutionalize their dying loved one. In the past, various forms of respite-like services have been implemented. They consist of day respite were the caregiver receives relief for several hours a day, night respite care, adult daycare, week-end respite and short-stay respite where the patient will stay five days at an in-patient facility (nursing home or long-term facility).

When used, the respite services have proven to be beneficial to the caregiver, but in some cases it was found that the assessment and recognition occurred late. For example, a study by Harding and Higginson (2003), found over 90% satisfaction among carers who received respite services, though 33% felt the service had been offered too late (p. 66). Within their study, Harding and Higginson recognized the stressful position of the caregiver, how the caregiver's needs were not being met, and the need for effective supportive services. Therefore, they conducted a systematic literature review of interventions used to help provide relief to caregivers of cancer and palliative patients. Their review resulted in a limited amount of targeted interventions as they identified 22 papers related to interventions in cancer and palliative care which targeted carers (Harding and Higginson, 2003). Due to varying designs across these 22 studies, Harding and Higginson were not able to complete a meta-analysis, but there were some insightful commonalities found within their research. They categorized the identified interventions into the following areas: home care, respite care, social networking and activities, one-to-one interventions, and group work. The intervention that provided the greatest caregiver

relief and level of satisfaction was that of respite care. The caregivers who used respite

services reported a 90% satisfaction rate and improvements in emotional stress, physical

stress, physical pain and sleep difficulty (Harding and Higginson, 2003). They found

home services (or home health) to be both satisfactory and useful, but it failed to meet all

of the caregiver's physical and emotional needs. The one-to-one interventions were

constructed in a manner to provide support, education, and build problem solving and

coping skills (Harding and Higginson, 2003) but they were rather expensive and required

additional time. There was no significant difference found on the outcomes of emotional,

social or physical function (Harding and Higginson, 2003) when using this intervention.

The group work intervention was helpful in providing support, information, coping skills,

and socialization to the carers but it may not be the most appropriate method for all

caregivers. Therefore, within this study, respite care was the best intervention for

decreasing caregiver stress, burden, and fatigue by decreasing both their physical and

emotional needs.

Unfortunately, many caregivers have experienced unmet respite needs.

According to Geiger and O'Neal (2014), under a federal grant, the Alabama Department

of Senior Services partnered with the Alabama Lifespan Respite Resource Network [TM] to

conduct a survey of 884 caregivers to determine if the respite needs of those caring for

patients with chronic illnesses or disabilities were being met. The results of this survey

would assist the Alabama Department of Senior Services in planning ways to educate the

caregivers and meet their respite needs. Their plan was to plan and implement better

access to respite resources for all Alabama family caregivers (Geiger and O'Neal, 2014)

through establishing the following goals:

1. Measure current capacity and improvement of the Respite Network as perceived by family caregivers, agencies, and providers.

2. Identify needed enhancements to respite worker training and service delivery.

3. Identify facilitators and barriers to a coordinated system of lifespan respite care in Alabama.

Their survey consisted of 49 questions that were grouped into the following categories: demographics, service needs, expectations of the caregivers, and the ability to identify service providers. A survey was given to 943 people, of which, 884 completed it. It was noted that not all completers responded to every item, so the total number of responses differed by item (Geiger and O'Neal, 2014). The survey revealed the following statistics that identified the unmet caregiver needs (Geiger and O'Neal, 2014):

- 20% reported received a Medicaid waiver for respite services.

- 69% never accessed caregiver respite services using a Medicaid waiver.

- 13% did not know if they had received waivers.

- 50% of the participants could not locate respite care at least once.

- 25% did not know how to request respite.

The participants who were informed about and used respite care praised its benefits and would feel stressed if respite were unavailable (Geiger and O'Neal, 2014). The other participants expressed the opinion, if offered, respite care would reduce their stress by allowing them relief from their caregiver responsibilities, allow them time to attend to other areas of their life, allow them time to care for other family members, and that they would need to receive assistance to pay for the respite services (Geiger and O'Neal, 2014). Nurses have the ability to change these statistics and assist in meeting the needs of

the caregivers by providing education, being patient advocates, assessing the need for and initiating the implementation of respite care.

The use of in-patient respite services contains several inconveniences for both the patient and the caregiver. For example, the patient transportation process and the fact that Medicare will only provide reimbursement if the patient is admitted to an in-patient facility is one of them. Should the caregiver desire to use any other type of respite-like services they will have to pay out-of-pocket, apply for a Medicaid waiver, or apply for additional sponsored grants and waivers to pay for the services. Therefore, through the use of Medicare, the patient must be transferred from their place of residence to an in-patient facility in order to receive in-patient respite care. The potential complications and stress of transferring a terminal patient between home and inpatient settings may impede the use of respite services substantially (Carlson et al., 2007). Additional contributing factors that may be related to the decreased use of respite services include the family's hesitance to use the service, and the caregiver's feelings of guilt. Some caregivers often struggle with complex emotions such as feelings of guilt and abandonment that impedes their ability to accept support services (Noelker and Browdie, 2012). Van Exel, de Graaf, and Brouwer (2008) recognized the low use of respite services and performed a study that explored the associations between the attitudes toward respite care, characteristics of the care giving situation, and the need and use of respite care (p. 73). They surveyed 273 caregivers and combined the results with their previous study "Care for a Break: An Investigation of Informal Caregivers' Attitudes Toward Respite Care Using Q-Methodology," to associate the limited use of respite care with the caregivers' attitudes and beliefs. They described three different types of caregiver attitudes toward respite

care: caregivers who need and ask for respite care, caregivers who need but will not ask for respite care, and caregivers who do not need respite care (van Exel et al., 2008). The caregivers who need respite services but will not ask for it are more likely to experience caregiver strain, fatigue, and burden. They need the help and assistance but are less likely to ask for it. These caregivers feel that it is their responsibility, are convinced that they are the best person to care for their loved one, or view relinquishing (even part of) the care as personal failure that lets the loved one down (van Exel et al., 2008). They also found that the care recipient also plays a role in the caregivers' reluctance to seek respite services. Some care recipients have a strong preference of being cared for by a specific individual and sometimes exercise psychological pressure on their primary caregiver to maintain the care giving task (van Exel et al., 2008), thus increasing the burden on the caregiver.

Nursing and the provided nursing interventions can decrease the risk of caregiver strain and/or burnout and improve outcomes achieved by the caregiver by reducing the contributing factors that inhibit the use of respite care. Many caregivers have identified the hospice nurse as their main source of information regarding care and resource needs and often cited the nurse as a source of emotional support (Newton, Bell, Lambert, and Fearing, 2002). The nurse is in the position to assess and identity caregiver strain and burnout, educate the caregiver on the effects of this issue, offer the available resources of respite care, and adequately implement the intervention of respite care in a timely manner. Due to the fact that identification and communication are essential in the prevention and intervention of hospice caregiver stress and burnout (Keidel, 2002, p. 200), it is the role of the nurse to routinely assess the caregivers and determine the need

of respite care, educate them on the process and the used resources to decrease their fears or hesitancies regarding the process. The created policy and procedure outlines the process, the nurse's role and responsibilities, when and how to use the adapted caregiver assessment tool, and all other established criteria needed to implement respite care.

Local Background and Context

The respite agency that was the subject of this DNP project did not have a standard rule, policy, or procedure that regulated any form of a routine caregiver assessment or identification of the need for respite care. Instead, the previous policy described the length of respite stay and the type of agency in which respite care is provided. Table 2.a describes the current respite policy used by the hospice agency. The agency usually provides respite services when the caregiver has some form of medical emergency that renders them disabled from caring for their dying loved one. For example, caregivers who have to undergo scheduled or unscheduled surgeries, hospitalizations, or experiences an illness that renders them debilitated. Occasionally, respite services are provided at the request of the caregiver due to planned vacations, but are seldom provided for caregiver strain or fatigue. Therefore, this project was led by published evidence to assist in the creation of policies and procedure that regulate the routine assessment of the caregiver to determine the need of respite care.

Table 1

Current Respite Policy

Inpatient care: Respite	Policy No. 819
Regulation(s) standards: 418.108, 418.100(b), 418.100(e), 418.204 GA 290-9-43.16	Effective date: May, 2013
	Revision(s) date:

Purpose: To ensure inpatient respite care services are available and properly used in accordance with State, Medicare and Medicaid regulations.

Policy: Respite care may be provided at an inpatient unit or in a Medicare or Medicaid certified facility. Inpatient care may be required for procedures necessary for pain control or acute or chronic symptom management or as a means of providing respite for the caregiver.

Procedure:
1. Respite services are available on an occasional basis and are provided to relieve caregivers. Respite may not be provided for more than five (5) consecutive days.
2. The facility providing respite care must provide 24-hour nursing services that meet the nursing needs of all patients and are furnished in accordance with each patient's plan of care.
   A. Patients receive all nursing services as prescribed and are kept conformable, clean, well-groomed, and protected from accident, injury, and infection.
3. Documentation in the clinical record for any change in level of care includes:
   A. Date and reason for change.
   B. Summation of the patient's status.
   C. Appropriate information for continuity of care.

The Walden University's online library was used to explore the EBSCO host databases of CINHAL, Medline, ProQuest Nursing and Allied Health, and Ovid. National websites such as the Centers for Medicare and Medicaid Services (CMS) (CMS.org) and the National Hospice and Palliative Care Organization (NHPCO) (NHPCO.org) were also used. The following key search terms were used to retrieve information: *respite, caregiver, hospice, respite care, carer, palliative care, interventions, caregiving, strain, burden,* and *fatigue.* Systemic reviews, randomized control studies, meta-analysis, mixed-

method case studies, and descriptive studies pertaining to caregiver burnout, fatigue, and respite care were retrieved in the past year to obtain supporting data. The literature was reviewed, critiqued, and analyzed for relevance and validity to obtain the most recent and most accurate information.

Definitions

Burnout is the physical, mental and emotional exhaustion that may lead to a feeling of resentment or loss of concern toward the person being cared for.

Caregiver burden and/or strain are the high levels of stress or overwhelming feelings that are experienced by caregivers due to caring for a person with a chronic medical illness.

Compassion fatigue is a form of burnout that is experienced by persons in a caregiver role.

Hospice care is the medical care provided to a terminally ill client who has less than six months to live, and the focus of care is to provide comfort and maintain the best quality of life instead of focusing on a cure.

Respite care is the temporary or periodic placement of a client into an accommodating facility outside of the home to provide short-term relief to the caregiver of their caregiver duties and responsibilities.

Respite-like services is any form of temporary relief that is designed to provide several hours of relief to the caregiver within one day. This includes, but is not limited to, daycare, paid sitters, volunteer services, and overnight relief.

Role of DNP Student

As a DNP student, I was able use the learned knowledge of evidence-based practices, leadership, nursing theory, project design and implementation to assist the hospice agency in improving care given to the hospice patient by meeting the needs of the hospice patient's caregiver. As a full-time nursing instructor and part-time hospice nurse, I was able to use the educational training and experience received during six years of teaching experiences, coupled with the evidence-based and project design education received as a DNP student. This knowledge and experience was used to design a program that will implement the needed changes to enhance the life of the hospice patient.

As a senior nurse, I have developed a rapport with the administrative and management team that allows fluent conversation and permission to address the needed issue of policy reform and enhancement as it relates to respite care. During the practicum experience, there have been several discussions about the lack of true direction in the current respite policy. The discussions included the declining use of respite care, the current policies related to respite care, and the need for improvements. Through casual conversation, the process has been discussed with the nurses, the director, the social worker, and the nursing administrator. All of the team members have provided their point of view related to the process and the need for changes with anticipation of future improvement.

The project was motivated by the belief of being able to provide the dying patient a dignified death while maintaining the best quality of life during their final days. It is a belief that if the caregiver is mentally, physically, and emotionally capable of providing loving and compassionate care to their dying loved one, they will do so in a way that will

best meet the patient's needs and final wishes while surrounding them with the love of their family. Ultimately, the dying family member is at the core of the problem because if the caregiver is stable and well they will ensure that the patient will be also. In essence, if the caregiver's needs are met they can meet the needs of the patient. Therefore, if there was a bias, it would be that of being the patient's advocate and ensuring that their needs are being met.

Role of the Project Team

The project team was comprised of the nursing staff, social worker, nurse manager, and the director. Each of these team members have a minimum of two years of hospice experience and possess knowledge of the process, the needs of the caregivers, and respite care.

The team began the process with a round table discussion during a scheduled meeting to discuss the benefits, limitations, and the known issues of respite care, their perceived remedies, and how this project will address it. The team was properly introduced to the project and informed on how this project will provide researched evidence to validate the use of respite care, the benefit to the caregiver and the terminally ill client, and how it can be used to prevent caregiver burnout and fatigue. They were informed on the proposed timeline of the project, the standard requirements, and their roles and responsibilities during the process. The team met on a bi-weekly basis to discuss the progress of the project and make any needed adjustments. During this time, they were presented with research and recommendations to enhance the current respite practice, they were able to discuss their perceptions of the project, provide input, and receive feedback on their propositions and the overall status of the project. During these

meetings there were continuous dialogue to explore all of the available options to create a respite program that was based on the needs of the agency, current research, the feasibility of addressing the needs of the patients and their caregivers, and preventing caregiver burnout and fatigue. The bi-weekly meetings continued until a finished product was produced, the caregiver assessment tool was adopted, and the respite policies and procedures were established. At that point, the meetings were decreased to monthly staff meetings to discussion and evaluate the newly developed respite program and any needed revisions.

During the bi-weekly meetings the stakeholders had the ability to provide formative feedback regarding the entire process, the creation of the respite policy and procedures, and the adoption and use of the caregiver assessment tool. This formative feedback was received, discussed, evaluated, and used in ongoing revisions to develop a policy and procedure that would be accepted and incorporated into the hospice agency's routine use. The stakeholders also had the ability to complete a summative project evaluation that will determine the validity and usefulness of this project, and the potential outcomes within the agency.

<p style="text-align:center">Summary</p>

Unfortunately, respite care has not been used to its highest potential due to lack of identification, caregiver reluctance, Medicare requirements, funding, and issues related to transportation. With the proper planning and guiding policies, this resource can be used in a way that will allow the caregiver to rest and recuperate, thus, allowing them the ability to provide the appropriate care to their dying loved one.

Section 3: Collection and Analysis of Evidence

Introduction

Hospice services have seen significant growth during the past 20 years and along with this growth come an increase in the number of caregivers caring for this dying population. These caregivers are often faced with an enormous amount of stress as they take on the physical, emotional, financial, and medical responsibilities of their dying loved one. They often stand in the need of some type of relief before they experience caregiver burnout and fatigue. Unfortunately, the intervention of respite (temporary caregiver relief) care is underused by the caregivers, and the hospice agency fails to properly use this service due to lack of policies and procedures that regulate the caregiver assessment, determination of need, and implementation of the respite process. This project established policies and guidelines that will routinely use an adopted caregiver assessment tool that will help identify the need for, and direct the implementation of, the respite process. In Section 3, I explore the practice-focused question and the sources of evidence.

Practice-Focused Questions

Increasing numbers of patients are placed under hospice care and are deciding to expire at home surrounded by their loved ones. In 2014, an estimated 1.6 to 1.7 million patients received services from hospice (NHPCO, 2015). These rising numbers have led to an increased number of caregivers who are faced with the strenuous task of caring for these patients at home. As it has been previously stated, significant potential exists for developing caregiver burnout and fatigue due to the various levels of stress in which

these caregivers are placed. Providing this kind of care to a loved one at the end of life can contribute to increased stress, health problems, and a decreased quality of life (Empeño et al., 2011). Caregivers report heart disease, arthritis, and diabetes at approximately twice the rate of individuals who are not family caregivers; depression, sleep disorders, and even death have been linked to the strain caregiver's experience (Leland, 2008; Span, 2009).

The gap in practice is the failure to prevent or respond to caregiver burnout due to the underuse of respite care. In 2014, an estimated 1.6 to 1.7 million patients received hospice services with only 0.4% of patient care days spent under respite care; this is a slight increase from the 0.3% in 2013 (NHPCO, 2015) (see Table 2). This underuse is due to the lack of regulatory guidelines that address how and when to perform a caregiver assessment, or how to determine the need for respite services.

Table 2

Percentage of Patient Care Days by Level of Care

Level of care	2014	2013
Routine home care	93.8%	94.1%
General inpatient care	4.8%	4.8%
Continuous care	1.0%	0.8%
Respite care	0.4%	0.3%

Note. NHPCO Facts and Figures on Hospice Care, 2015 edition.

According to the CMS (2015), respite care is short-term inpatient care provided to the individual only when necessary to relieve the family members or other persons who

normally care for the individual at home. It does not provide any additional information

or regulations on what caregiver characteristics constitutes a need for respite care, how to

determine the need for relief, or how often an assessment of need should be performed

(see Appendix A). The CMS does provide instruction on the type of facility in which

respite can be performed or the respite length of stay, and it states that the purpose of

respite care is to provide caregiver relief or patient pain management. The lack of

instructions regarding characteristics that display the need for respite care allows the

hospice agency to refrain from having policies and procedures that govern a routine

caregiver assessment and the implementation of respite care. Therefore, I guided my

study with the following question: How can an evidence based caregiver respite program

be established within the hospice agency? I addressed this question by creating a policy

and procedure that provide guidelines on the routine use of an adopted caregiver

assessment tool that will assess the caregiver for burnout and/or fatigue, outline the

procedures of implementing respite care, and provide a respite care checklist to ensure all

of the needed requirements are followed and met for a smooth patient transition.

Sources of Evidence

To gather information, plan, and complete this project, I relied heavily on

research materials. I used the Walden University online library, along with various

national websites and databases such as the CMS (CMS.org) and the NHPCO

(NHPCO.org) to gather evidence-based practices and research studies related to caregiver

burnout, strain, and the use of respite care. I retrieved systemic reviews, randomized

control studies, meta-analysis, mixed-method case studies, and descriptive studies

pertaining to caregiver burnout, fatigue, and respite care to obtain supporting data. The

literature was reviewed, critiqued, and analyzed for relevance and validity to obtain the most recent and most accurate information.

Team discussions on current evidence based practices, research on respite care, and current methods of practice led to the development of the respite program. Through the use and comparison of research the team was be able to provide and receive feedback on the inadequate nature of the current policy, adopt a caregiver assessment tool and understand how the newly reformed respite program can be used to improve both the patient and the caregiver's outcomes.

The literature review supported the need for respite care, proven it to be a valuable resource, and it provided various examples of theories and assessment tools that could be used within the project. For example, literature by Phillpson, Jones, and Magee (2014) used Anderson's Behavioral Model of Service Use to provide a theoretical explanation as to why caregivers decide not to use respite services. This information serves as a great asset to this project because it provides the model used as the theoretical framework to help address the caregiver's feelings or thoughts toward respite care, and address the fact that only 7% of the eligible caregivers actually use this service (Carlson et al., 2007). Anderson's behavioral model provided the team guidance during the review of caregiver assessment tools. The project team placed emphasis on the fact that the chosen tool should screen for burnout and fatigue, while also identifying the presence of factors that could interfere with the acceptance of respite services.

The proposed caregiver assessment tool used for this project is that of the Caregiver Reaction Assessment (CRA). The CRA (see Table 3) was developed in the United States by researchers at Michigan State University, whose purpose was to obtain a

multidimensional tool suitable for burden assessment of family caregivers of people

suffering from chronic physical and mental diseases (Given et al., 1992). The CRA

consist of 24 assessment questions using a 5 point Likert scale ranging from strongly

agree to strongly disagree. It focuses on both the positive and negative aspects of

caregiver esteem, the lack of family support, and the effect on the caregiver's health,

finances, and schedule (see Appendix B). Caregivers who rate strongly on Questions 10,

19, 12, 6, 4, 15, and 21 fall under the self-esteem subscale that exhibits positive reactions

toward providing care. Caregivers who achieve significant scores on Questions 14, 20, 7,

16, and 1 will express how caring for their dying loved one has greatly affected their

daily life and schedule. Those who score high on Questions 13, 11, 17, 9, and 3 will

display their lack of additional support from family members and/or friends. Questions

23, 24, and 22 represent the financial strain that providing care has placed on the

caregiver. Last, Questions 2, 8, 5, and 18 represent how providing care has affected the

caregiver's personal health. For each subscale, a total score will be calculated as the

average of the subsequent item scores ranging from 1 to 5 (Yang, Shin, Kim, Sho, Shun,

Son, & Park, 2013). A higher score indicates a higher level of caregiver burden, except

for scores on caregiver's self-esteem, for which higher scores indicated less caregiver

burden (Yang et al., 2013).

The instrument has been translated and validated in Germany, Netherlands,

Sweden, Norway, Portugal, Korea, Japan, China, and Singapore, revealing satisfactory

parameters of validity and reliability in different cultures (Rochelly, Fonseca, da Silva,

Peixoto, Lira de Amorium, Ligia, & Barbosa, 2015). Reliability analysis showed that

standardized Cronbach's α's varied between 0.62 and 0.83 for the separate subscales,

indicating sufficient internal consistencies (Nijboer, Triemstra, Tempelaar, Sanderman, &

van den Bos, 1999). Test-retest reliability over a two-week period revealed that all scales

consistently assessed burden over time, $r = 0.62$ to 0.87, and the convergent validity

evidence was positive with another measure of caregiver burden ($r \geq .56$) (American

Psychological Association, 2016).

Table 3

Caregiver Reaction Assessment Scale

Items constituting the caregiver assessment scale[a]					
Items	I totally disagree	I disagree	I neither agree nor disagree	I agree	I totally agree
1. My activities are centered around care for...	1	2	3	4	5
2. I am healthy enough to care for..[b]	1	2	3	4	5
3. My family works together at caring for...[b]	1	2	3	4	5
4. Caring for... is important to me	1	2	3	4	5
5. It takes all my physical strength to care for...	1	2	3	4	5
6. I enjoy caring for...	1	2	3	4	5
7. I have to stop in the middle of my work or activities to provide care	1	2	3	4	5
8. My health has gotten worse since I've been caring for...	1	2	3	4	5
9. Since caring for..., I feel my family has abandoned me	1	2	3	4	5
10. Caring for... makes me feel good	1	2	3	4	5
11. It is very difficult to get help from my family in taking care of ...	1	2	3	4	5
12. I feel privileged to care for...	1	2	3	4	5

table continues

Items	I totally disagree	I disagree	I neither agree nor disagree	I agree	I totally agree
13. Others have dumped caring for... onto me	1	2	3	4	5
14. I have eliminated things from my schedule since caring for...	1	2	3	4	5
15. I resent having to care for... [b]	1	2	3	4	5
16. The constant interruptions make it difficult to find time for relaxation	1	2	3	4	5
17. My family (brothers, sisters, children) left me alone to care for...	1	2	3	4	5
18. Since caring for... , it seems like I'm tired all of the time	1	2	3	4	5
19. I really want to care for...	1	2	3	4	5
20. I visit family and friends less since I have been caring for...	1	2	3	4	5
21. I will never be able to do enough caregiving to repay ...	1	2	3	4	5
22. Financial resources are adequate[b]	1	2	3	4	5
23. It is difficult to pay for...	1	2	3	4	5
24. Caring for... puts a financial strain on me	1	2	3	4	5

[a]CRA scale version by Nijboer et al. (1999).
[b]Reverse scored.

The current policy has failed to address the subject of performing a caregiver assessment, provide criteria for respite care, or explain how to carry through the respite process. The lack of a reliable policy has contributed to the lack of respite use, which leads to increased caregiver burden and poor client outcomes. Research has provided true

evidence that caregiver burden and fatigue does exist, and that it is a topic in need of

addressing. A study by Van Exel, Moree, Schreuder Goedheijt, & Brouwer (2006)

assessed the demand and use of respite care among informal caregivers and concluded

that one in three of the caregivers who actually used respite services found that if respite

care were not available they would experience an increase in their level of burden, and

half of the caregivers who did not use respite services within the study admitted to

needing it and believing that it would decrease their burden. Van Exel et al. (2013)

conducted this study because they wanted to gain additional information on the use of

respite care, the needs and the wants of informal caregivers. They surveyed 273

caregivers and found that the participants within the study were reasonably well informed

about existing services, especially out-of-home services; least informed was a subgroup

that needs but currently does not make use of respite; they found that only one-third of

the participants used respite services (Van Exel et al, 2013).

The results from the previously mentioned study provided significant points of

discussion during the team meetings, and it further solidified the need for the agency to

revise the current policy and increase the use of respite care, thus, relieving the caregivers

of their burden and ultimately enhancing the patients' outcomes and level of satisfaction.

The study addressed the benefits of respite care and how it can negatively affect the

caregivers who fail to use this service, serving as the driving force behind the team's

revision and creation of a valid respite program, to include a revised policy and a defined

implementation process.

The scope of this DNP project is limited to the development and planning of the

project only. Therefore, I played an instrumental role in gathering research and evidence

that aided in the review of tools and the development of policy documents. Within this project, the I was responsible for leading the team in the development of a revised respite program that includes a revamped respite policy, the adoption of a caregiver assessment tool, and the creation of respite implementation guidelines for a fully developed respite program. The entire team analyzed, discussed, and revised the current respite documents, adopted the CRA as the assessment tool for burden and/or fatigue, redesigned and refined the respite implementation procedure, and evaluated these documents and procedures for their ease of use, understanding, and ability to implement. The team had regularly scheduled meetings to discuss and provide feedback on the program's development. This formative feedback will aide in the evaluation of the program and serve as process evaluation of the project. At the completion of the project planning stage the stakeholders performed a formal project review, provide relative feedback, and completed a summative evaluation of the process, project, and leadership of the DNP student (see Appendix C).

Upon completion of the project, I supplied the hospice agency with all of the program documentation and deliverables. These deliverables include a complete plan for a caregiver assessment and respite implementation that will allow the hospice nurses to begin implementing the policy by performing routine biweekly caregiver assessments on the caregivers of the clients serviced by the hospice agency using the adopted CRA tool. After performing the assessment, receiving and analyzing the caregiver's responses to the questions on the caregiver tool the registered nurse, medical director, social worker, and the director of nursing will determine the need for respite care and begin the respite care implementation process as it is outlined in the revised policy.

Following implementation, the team will continue to meet on a monthly basis to evaluate the program and its effectiveness. At this time, the nurses will continue to share the results of the bi-weekly caregiver assessments, discuss the use of the CRA, its ease of use, and its ability to identify any caregiver(s) who displayed signs of potential caregiver burnout and/or fatigue. The team will identify the caregivers who are in need of respite care, or other supportive services, by reviewing the caregivers' results on the CRA. They will identify those who achieved high CRA scores in the areas related to caregiver burden (lack of family support and the effect on schedule, financial, and health subscales), review their verbal reactions and/or request for assistance, and describe their physical and emotional behaviors. A higher score on the caregiver esteem subscale indicates a more positive effect on caregiving, and higher scores on the other four subscales indicate greater negative effects of caregiving in those domains (Given et al., 1992; Nijboer et al., 1999).

The team will share if any identified caregiver(s) participated in respite services or not (including the reasons for decline), and discuss the status and/or condition of those caregivers who did participate in respite services. The team will determine if the caregiver's mental, physical, and emotional condition has improved by analyzing the CRA scores that were obtained prior to respite services to the scores following respite services to determine the effectiveness of the CRA's ability to identify burden or fatigue, and to determine if respite care was effective in preventing caregiver burnout and /or fatigue. These results will also be compared with the assessment scores of those who were identified as needing respite care but declined to use the services. It is the expectation that the caregiver's assessment scores will display a numerical decrease

following the use of respite care, and that those caregivers who declined to use respite

care will continue to produce higher numerical scores; thus, validating the effectiveness

of the adopted caregiver assessment tool, the use of respite care, and the need of a routine

caregiver assessment.

The information gained during these various monthly meetings will be used to

determine the program's ease of use and effectiveness, and if the goal of preventing

caregiver burnout or fatigue has been met. The team will have the ability to make

adjustments to the process as needed based on the program outcomes. They will have the

ability to refer to the final project report, review any previous notes, reference materials,

meeting minutes, comments, and recommendations.

Summary

It is widely accepted that supporting individuals to die at home relies heavily on

the availability of family carers to provide the majority of the care needed (Skilbeck,

Payne, Ingleton, Nolan, Carey, & Hanson, 2005). Many of these caregivers require some

type of relief, or respite care, to allow them a physical, mental, and emotional period of

relief. To supply the best care to the dying patient, the hospice company must address the

subject of caregiver burnout and fatigue by creating a routine assessment system that will

identify the needs of the caregiver and determine the need of temporary relief. This can

be done by accurately using research as a guide to gain a greater understanding of the

caregiver's need and produce valid tools that can be used by the agency.

Section 4: Findings, Discussion, and Implications

Introduction

Respite care has been significantly underused by caregivers of terminally ill

patients, leading to an increased risk of caregiver burnout and/or fatigue. For example, an

estimated 1.6 to 1.7 million patients in the United States received hospice services in

2014 with only 0.4% of patient care days spent under respite care, and only 0.3% in the

previous year (NHPCO, 2015). Therefore, many caregivers were tasked with caring for

their dying loved one at home. Providing this kind of care to a loved one at the end of life

can contribute to increased stress, health problems, and a decreased quality of life

(Empeño et al., 2011). One contributing factor to this gap-in-practice is that of the

hospice agency's failure to provide adequate policies and procedures that outline when

and how to assess a caregiver for the need of respite care assistance, exactly what

constitutes the need for respite care, and how to implement it.

The purpose of this project was to plan a respite program within the hospice

agency that included policies and procedures that directs the routine assessment of

caregivers to determine when, or when not to, implement respite care, and to provide an

outline of the respite implementation process. The creation of this policy and procedures

was done through the review and analysis of a variety of systematic reviews, randomized

controlled studies, meta-analysis, case studies, and descriptive studies. The research

literature helped solidify the need for respite care and the benefits of using this service,

and it provided a variety of assessment tools and methods that can be used to assess the

caregiver. In Section 4, I discuss the findings and implications of the project, any

identified recommendations, contributions of the project team, and strengths and limitations of this doctoral project.

Findings and Implications

Throughout this project, the team met on a consistent basis to develop the new policy and procedures. Oftentimes, the meetings were shortened due to patient needs and scheduling, but for the most part the team was present and willing to participate. Due to the small nature of the group (seven persons including the student author of this DNP project), it was vital that everyone was present during the meetings to remain on task. Therefore, rescheduling had to occur several times to obtain full participation.

During the meetings, the nurses were the most vocal within the group, due to the fact that they would serve as the actual initiators of the caregiver assessment. They voiced some concerns on the time, length, and convenience of the assessment. Therefore, the team spent much time and consideration in the adopting of a caregiver assessment tool that would satisfy the nurses while meeting the needs of the caregivers. After reviewing multiple assessment tools, the team chose to use the Caregiver Reaction Assessment (CRA) tool due to the fact that it is short, direct, easy to use and interpret, and has the ability to determine the needs of the caregivers. Once this tool was chosen and agreed upon for adoption, the nurses placed much debate on the implementation process. They did not want this process to lengthen their visit time, but, with administration's help and direction, the biweekly assessment option was chosen and agreed upon by all members. The chaplain and social worker were vocal in their ideas and thoughts but they were frequently willing to defer to the opinions of the nurses to smooth the process. As a leader, I found that it was vital that each member of the team

understood their role, freely shared their knowledge, and offered suggestions to obtain a successful outcome. Therefore, special efforts were taken to allow them to offer suggestions, consider and defend them, and coach the team into choosing the options that were best for all of the stakeholders within this project.

Overall, the team members worked well with one another. This was largely because the team members have worked together for several years. The newest member of the team has worked there for 2 years. Their extensive knowledge base of multiple years within the hospice industry offered the team great insights on policies, ethical and legal matters, caregivers and patients' needs and reactions. The team's extensive level of knowledge and experiences allowed for a rather smooth transition and the creation of a new policy.

Additional findings throughout this project were that of the project evaluations. As stated earlier, the entire team was very instrumental in providing formative feedback throughout the process with 100% participation on a consistent basis. The team also provided 100% participation with the summative feedback (See Appendix C). The team evaluations resulted in 100% of them members either "agreeing" or "strongly agreeing" that the project problem was made clear, the student analyzed and synthesized the evidence, and that the program goal was appropriate. The majority of the team (83.3%) "agreed" or "strongly agreed" that the project objectives where met while 16.7% remained neutral. There were comments that they were unable to fully provide an answer to this question due to the lack of implementation and analysis of the outcomes. It is noted that implementation cannot occur until the agency sends the documents to corporate for legal and ethical review, receives clearance, and are authorized to begin

implementation. Under the areas of the DNP student leadership, productive meetings, and team member input within the process the team responded with 100% "agree" or "strongly agree". When it came to sending out meeting agendas and minutes, 83.3% of the team "agreed" or "strongly agree" while 16.7% remained neutral. There were no comments or explanation for these results. The last results addressed the meeting times and allotment. Most (66.7%) of the team members "agreed" or "strongly agreed" that the meetings were held in their allotted time, 16.7% remained neutral, and 16.7% "disagreed". This result was expected due to the rescheduling of meetings to meet the team member's needs.

Overall, the project team members and the administrative team provided positive feedback regarding the doctoral project. They were very receptive to the process of change, pleased with the level of leadership, and satisfied with the ending result of a revised respite policy and procedures.

The newly revised policy and procedure has the ability to enhance the outcomes of both the caregivers and the terminally ill client by providing the caregiver with the appropriate interventions and support to adequately provide care to their dying loved one. If the caregiver feels as though he or she has adequate support and less of a burden, he or she may remain in optimum health, refrain from mental, physical, and emotional dismay, and may be able to better meet the needs of their loved one(s). At this point the dying client may receive the satisfaction of having their needs, wishes, and desires met while being allowed to remain at home surrounded by their loved ones during their last days of life. This in return, can benefit the agency because the clients and caregivers will be more likely to recommend or refer the agency to others whom they may know. Caregiver

satisfaction can also increase the hospice agency's satisfaction surveys and rating. Other ways this can benefit the agency is by having an established procedure and policy that is transparent and easily followed by both present and future employees of the agency. This will allow for less questions and confusion on how to determine the need for respite care.

The revised policy and adoption of a caregiver assessment has the ability to serve as an example for other hospice agencies by provoking them to do the same. If multiple hospice agencies adopt this method it can evoke a positive social change in the hospice profession by issuing a routine caregiver assessment, addressing the caregivers' needs and not just those of the hospice patient. This will let them know that their role is vital in this process, it can decrease their risk of a potential health issues, increase their overall level of satisfaction, and it can positively influence the overall perception of hospice care and caregiver's roles. It also has the potential to raise question to the CMS and NHPCO as to the need to establish some type of national regulation that will guide the hospice agencies into a uniform way of assessing and establishing the need for respite care.

Recommendations

In light of the findings, it was recommended, and eagerly accepted, that the agency revise its previous minimal respite policy and procedures, adopt a formal assessment tool that will be used to assess the caregiver for burden and/or fatigue, identify the caregiver outcomes that warrants intervention and/or respite care, and clearly identify the steps needed to implement respite care. The doctoral project team began by revising the purpose of the new policy from "To ensure inpatient respite care services are available and properly utilized" to that of "Establishing the criteria for admitting a patient to respite care". According to the new policy, the new criteria for respite care now

includes, but is not limited to, situations and occurrences of high scores on the CRA tool, medical emergencies, caregiver incompetence, and/or absences. See Appendix D for the new policy). The team also felt as though it was important that the new policy address patients who are not covered by Medicare/Medicaid, the responsibilities of the hospice agency personnel as it relates to respite care, and the actual procedure of implementing respite care. Therefore, the new policy now defines the personal financial responsibility of patients who are not covered by Medicare/Medicaid as that of the patient and not the agency, it clearly states the roles and responsibilities of the hospice personnel, and it provides the steps taken to implement respite care. Appendix D displays the new policy and respite care procedure.

The team analyzed various methods of caregiver assessments and concluded with the adoption of the Caregiver Reaction Assessment (CRA) tool to perform biweekly caregiver assessments during routine skilled nursing visits to help determine the caregiver's needs. The CRA has been widely used in different continents and provides a wealth of information on the burden of informal caregivers throughout the world (Mota et al., 2015). With its consistent reliability and validity rate amongst several countries throughout the world, the CRA has shown itself to be a good option for studying the subjective, multidimensional, negative and positive experiences of caregiving among caregivers (Nijboer et al., 1999). This tool will aid in determining the need of respite care, or lack of, by calculating the caregiver's numeric value within four of the five categories within the assessment tool. For example, caregivers who expressed high levels of burden or strain by choosing "Agree" or "Strongly Agree" under the areas of disrupted schedule, lack of family support, financial problems, and health problems categories on

the CRA (See Appendix B for the breakdown of categories and scoring ranges) will result in relatively high scores and are deemed to be "in strong need of intervention". While those who choose "Disagree" or "Strongly Disagree may not be in need of immediate intervention and will continue to be monitored and/or assessed on a biweekly basis.

The agency will manage the caregivers based on their assessment results and perform the appropriate actions as they are recommended by the Interdisciplinary group. The Interdisciplinary group consists of the Medical Director, the Director of Nursing, the primary nurse, the chaplain, and the social worker. After reviewing the caregiver's CRA results, the Interdisciplinary group will meet to discuss each individual case and identify a possible need for respite care. Any caregiver who obtains high scores on the CRA by answering "strongly agree" will receive a recommendation for respite care. Please note, that not all caregivers will agree to respite care, therefore, the alternative interventions are considered.

Those who achieve moderately high levels on the assessment scale will be placed in the category of needing "discussion and follow-up care". These caregivers are at risk of entering into the danger zone of burnout and fatigue. At this point, the agency will need to discuss the situation at hand, identify any areas of needed interventions, help the caregiver find relief or solutions, and continue to follow-up as needed. The alternate solutions may include assisting the caregiver with scheduling issues, providing caregiver education and stress relief information, and identifying other methods of relief such as using sitters, family, friends and volunteers. Also, the chaplain and/or social worker could come in for spiritual counseling, evaluation and application of sponsorship or voucher

programs that will pay for temporary sitters. At the time steps will be taken to prevent the caregiver from entering into the area of needing respite care.

Last, caregivers who score within the "continue to monitor" ranges will express no need of intervention but will continue to be monitored on a biweekly basis. Caregivers who show no need of consideration of intervention will be those who respond with a "Disagree" or "Strongly Disagree" on the Likert scale. These caregiver's express no apparent need or problem and are at low to no risk of burden or strain. The scores within the self-esteem category are null and void because they are positive indicators and do not indicate a caregiver need.

Due to the nature of this doctoral project, the implementation will be at the discretion of the hospice agency following the completion of project. The agency's administrative team is willing to accept and implement the changes but will have to send the proposed policy and procedures to the cooperate office for further examination to ensure all legal and ethical aspects are met. Once corporate clearance is achieved a copy of the finalized policy and procedures, the CRA tool, and the scoring matrix will be disseminated to the agency during the monthly staff meeting. It is recommended that the agency perform an educational process to review, discuss, and evaluate the nurses on how to properly administer the assessment prior to implementation. The Director of Nursing should lead this in-service and provide the nurses with the proper education. The nurses must fully understand the fact that they are not to coerce or influence the caregiver's responses in any way. They can have the option to allow the caregiver to independently answer the questions on the assessment tool quietly, or they can read the questions aloud without providing influences.

During the in-service, it is recommended that they review the meanings and actions associated with the caregiver's results and how to provide timely responses to administration and the Interdisciplinary group. It is also recommended that the chaplain and social worker attend the in-service so that they can receive the proper education on their roles of relaying information to the appropriate persons, and on their roles and responsibilities during the implementation process. Following the in-service, it is recommended that all of the attendees sign a statement stating that they have received the new policy, have full understanding, and was allowed to answer questions and receive answers.

Last, it is recommended that they perform formative evaluations during their routine biweekly meetings to discuss the use of the tool. After three months' time, they should perform a summative evaluation and discuss the CRA's ease of use of, the results found, and the tool's ability to identify the needs of the caregiver. At this point, the agency will compare the caregivers' pre- and post-intervention results to determine the effectiveness of the performed interventions. Caregivers should achieve decreased or lowered scores post intervention and/or respite care, thus, lowering the risk of caregiver burnout and/or fatigue. The agency can review these results and make any necessary adjustments to fit the needs of the agency while continuing to monitor on an ongoing basis.

Contribution of Doctoral Project Team

The doctoral project team was very instrumental in the development of this project. The team met on a biweekly basis to review the literature, analyze and discuss the findings, and make revisions as necessary. Everyone on the team provided formative

feedback through both written and verbal forms to ensure equality and consideration of everyone's input. As the student and team leader, it was my job to act as the change agent, present new ideas, achieve buy in, and provide the team with research and literature related to the project. I facilitated conversations and organized the meetings as well as present and analyze the old policies.

The nurses, chaplain and social worker were instrumental in discussions, providing feedback, alternatives, and suggestions that ensured the usefulness and feasibility of the newly revised policy. The nurses were able to provide input on the usefulness of the CRA, its administration, and caregiver's reactions to it. The chaplain provided the spiritual aspect of the caregiver's needs, the importance of meeting those needs, and provided insight on the nonverbal cues of the caregivers; and the social worker was able to provide information of the various options and interventions that could be used and obtained to meet the caregiver's needs.

The administrative team provided the needed authorities and ensured that all of the procedures were carried out within the rules and regulations of the agency. The administrative team also met with me on a regular basis to ensure the needs of the project were available, and that I was remaining on task and within the scope of the project. The administrative team also had the ability to add an executive summary at the conclusion of their evaluation to provide detailed input regarding my overall performance, achievements, and needed areas of enhancements.

All members of the team were instrumental in revising the policy and ensuring the coverage of discussion on all areas by providing their formative feedback in every step of the process. They assisted in proofreading, analysis, and comparison of the new policy

and procedures against the old one, the CMS requirements, and the objectives of the project. The administrative team had the final say as they ensured all areas of the final product were in compliance with the agency, and within the CMS rules and regulations.

It was the goal of the entire team to place these newly revised policy and procedures into practice within the agency at the conclusion of this project, and upon the receipt of corporate clearance. Once cleared, the agency will then have the ability to perform their own evaluation to ensure the policy's effectiveness and make the necessary changes and adjustments based on their findings after implementation.

Strengths and Limitations

There were many strengths found within this project. Some of those being the diversity, knowledge, and experiences found within the project team members. The diverse nature of the team members and their roles allowed the team to understand the information from all points-of-view. Due to the team's diverse nature it acquired input from the various areas of compassion, need, spirituality, and culture on a consistent basis. This allowed the team to create a product that will meet the needs of all of the patients while considering those of the caregivers. All of the members possess a minimum of two years of in depth hospice experiences, and many of them had ten years or more. This provided the team with a wealth of knowledge related to hospice procedures, Medicare and Medicaid regulations, as well as state regulations. This helped the team consider both the legal and ethical nature of the project.

The project's limitations lie within the fact that there was limited guidance from the National levels of the Centers of Medicare and Medicaid Services and the National Hospice and Palliative Care Organization in relation to performing a caregiver

assessment in determining the need of respite care. The adoption and use of the CRA is a

good start but the outcomes and usefulness will not be determined as valuable to the

agency until it has been implemented.

Section 5: Dissemination Plan

At the completion of this project, the information will be disseminated to the hospice agency via completed documents and deliverables. The hospice agency will receive a final report that includes the revised respite policy and procedures containing a detailed respite implementation process. The agency will also receive copies of the CRA tool along with the key containing the five dimensions and scoring ranges, and detailed instructions on the use of the assessment tool. Last, the agency will receive a detailed summary of the caregiver assessment process, the frequency, and associated interventions. The agency will have in its possession all of the meeting notes taken by their administrative assistant to refer to if any additional questions arise.

Based on the nature of this project, this information can be disseminated to any hospice agency that is in need of an evidence-based method of assessing the caregivers for the need of respite care. This information is not limited to only hospice agencies. It can be used by any home health agency that oversees the care of terminally ill clients of all ages; those supervising the home care of clients with severe, life-altering illness and diseases such as Alzheimer's and dementia; pediatric patients with a high acuity, or any patient who receives complete care from their caregivers while remaining in the home. This information can also be used during platforms presented by any national or local hospice or home health organizations, and it can be presented on any of the NHPCO platforms, websites, and/or conferences.

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Analysis of Self

This project has allowed me to gain a wealth of knowledge when it comes to the areas of respite care, caregiver burnout and fatigue, and the Centers for Medicare and Medicaid Services's rules and regulations. As a former home health/hospice nurse, I was unaware of the value and importance of respite care until this project. Through the act of seeking my Doctorate in Nursing Practice degree I have uncovered a side of nursing that I knew existed, but never showed great interest in, because I felt as though it was someone else's job. I always performed my duties as I was told without lending much thought to the research and work behind it. This doctorate program and project has allowed me to gain a better understanding of the importance and process of evidence-based practice and the implementation of best practices.

In my new role as a practitioner, I am able to understand the importance of acknowledging the needs of the caregiver in order to care for the patient holistically. It is so often that one places great focus on the patient without giving much thought to the wellbeing of the caregiver. Not acknowledging the fact that the caregiver is the patient's source of sustenance. As a nursing instructor, I have always instructed my students to look at the whole patient and provide a holistic approach. Now I will place more focus on ensuring the needs of the caregiver are met to enhance the outcomes of the terminally ill patients.

In my new role as a scholar, I have gained a deeper understanding of research and application. This program and dissertation process has made me strive for greater heights when it comes to my profession. I have begun to take on additional scholarly activities as I prepared for and achieved my Certified Nurse Educator credentials. I am eager to bring

forth new evidence-based practices at work, and I now refer to the data and supporting documents more now than I have throughout my entire nursing career. This dissertation process has allowed me to see a project through from the beginning to end while using and relying on research throughout the entire process. I now know and understand the process of change based on best practices, and I am not afraid to initiate and implement it now.

Finally, during my role as a project manager I captured a wealth of knowledge that will allow me to become a better leader. I use to refer to the laissez-faire, authoritative, and democratic leadership styles but I know refer to the transactional and transformational leadership styles. As a project manager, I had to wear multiple hats when it came to a style of leadership. I understand the importance of achieving buy in from the stakeholders, and the value in ensuring their feeling of support when it comes to project achievement and success. My goal is to continue to present myself as a leader who supports, acknowledges, and respects my team for all of their hard work and dedication.

In the beginning of this scholarly journey I felt overwhelmed, loss, and confused. This was difficult for me because I am normally a rather confident person who has achieved every goal set before me. In the past I considered myself to be pretty self-sufficient and refrained from asking others for help. Throughout this journey, I have learned that I have to humble myself, ask questions, and seek the assistance of others in order to grow and gain the necessary knowledge for success. The solution to many of my problems was that of seeking further assistance and requesting a clearer understanding. This assistance came from my instructor, preceptor, fellow students, or the administrators

at the practicum setting. This has allowed me to grow both personally, professionally, and academically.

Summary

The hospice industry has seen a significant growth over the last few years due to the number of people who desire to expire at home surrounded by their loved ones and personal belongings. With this increased number of hospice patients come an increased number of unskilled caregivers who are tasked with providing their dying loved one's care. This has placed an increased amount of stress on the caregivers, thus, increasing their risk of physical, mental, and emotional illnesses. The added stress increases the chances of inadequate care given to the patients from the caregivers. Therefore, it is imperative that the hospice agencies make every effort to meet both the needs of the patients and the caregivers to ensure the best possible patient/caregiver outcome. This can be done by the correct identification of the need for, and the implementation of respite care. Unfortunately, the use of respite care has been very low in spite of the large number of hospice patients. This is partly due to the lack of any national, state, or local guidelines on how to determine the need for respite care. In this project, a respite policy was developed. This plan includes instructions for the use of a caregiver assessment tool and management based on the tool results, as well as a plan for implementation. The new policy will be evaluated by the hospice agency's administrative team, the registered nurses, the chaplain and the social worker for its ease of use, effectiveness, and validity. The use of this new procedure will help identify caregiver burden and/or fatigue, identify the needed interventions, and provide respite care services when applicable to obtain the best possible outcome for both the patient and the caregiver.

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Appendix A: Medicare Benefit Policy Manual Excerpts

Chapter 9 - Coverage of Hospice Services Under Hospital Insurance

(Rev. 209, 05-08-15)

Section 40.2.2 - Respite Care

(Rev. 188, Issued: 05-01-14; Effective: 08-04-14; Implementation: 08-04-14)

Respite care is short-term inpatient care provided to the individual only when necessary to relieve the family members or other persons caring for the individual at home. Respite care may only be provided in a Medicare participating hospital or hospice inpatient facility, or a Medicare or Medicaid participating nursing facility. Respite care may be provided only on an occasional basis and may not be reimbursed for more than 5 consecutive days at a time. Respite care provided for more than 5 consecutive days at a time must be billed as routine home care for day 6 and beyond, and the patient may be liable for room and board charges for day 6 and beyond. See §40.1.5 for additional information (CMS, 2015).

40.1.5 - Short-Term Inpatient Care

(Rev. 188, Issued: 05-01-14; Effective: 08-04-14; Implementation: 08-04-14)

Short-term inpatient care may be provided in a participating hospital, hospice inpatient unit, or a participating SNF or NF that additionally meets the special hospice standards regarding patient and staffing areas. Medicare payment cannot be made for inpatient hospice care provided in a VA facility to Medicare beneficiaries eligible to receive Veteran's health services. Services provided in an inpatient setting must conform to the written plan of care. However, dually eligible veterans residing at home in their community may elect the Medicare hospice benefit. See §60.

Medicare covers two levels of inpatient care: respite care for relief of the patient's caregivers, and general inpatient care which is for pain control and symptom management. General inpatient care (GIP) may only be provided in a Medicare participating hospital, SNF, or hospice inpatient facility. Respite care may only be provided in a Medicare participating hospital or hospice inpatient facility, or a Medicare or Medicaid participating nursing facility.

General inpatient care is allowed when the patient's medical condition warrants a short term inpatient stay for pain control or acute or chronic symptom management that cannot feasibly be provided in other settings.

General inpatient care under the hospice benefit is not equivalent to a hospital level of care under the Medicare hospital benefit. For example, a brief period of general inpatient care may be needed in some cases when a patient elects the hospice benefit at the end of a covered hospital stay. If a patient in this circumstance continues to need pain control or symptom management, which cannot be feasibly provided in other settings while the patient prepares to receive hospice home care, general inpatient care is appropriate.

Other examples of appropriate general inpatient care include a patient in need of medication adjustment, observation, or other stabilizing treatment, such as psycho-social monitoring. It is not appropriate to bill Medicare for general inpatient care days for situations where the individual's caregiver support has broken down unless the coverage requirements for the general inpatient level of care are otherwise met. For a hospice to provide and bill for the general inpatient level of care, the patient must require an

intensity of care directed towards pain control and symptom management that cannot be managed in any other setting.

Respite care is short-term inpatient care provided to the individual only when necessary to relieve the family members or other persons who normally care for the individual at home. Respite care may be provided only on an occasional basis and may not be reimbursed for more than 5 consecutive days at a time. Payment for the sixth and any subsequent day of respite care is made at the routine home care rate, and the patient would be liable for room and board. Respite care cannot be provided to hospice patients who reside in a facility (such as a long-term care nursing facility). Provision of respite care depends upon the needs of the patient and of the patient's caregiver, within the limitations given.

Several examples of appropriate respite care for a patient who does not reside in a facility include providing a few days for the caregiver to rest at home, to visit family, attend a wedding, or attend a graduation for a needed break, or providing a few days immediately following a GIP stay if the usual caregiver has fallen ill. See also, section 40.2.2.

Note that hospice inpatient care in an SNF or NF serves to prolong current benefit periods for general Medicare hospital and SNF benefits. This could potentially affect patients who revoke the hospice benefit.

If a hospice patient receives general inpatient care for 3 days or more in a hospital, and chooses to revoke hospice, then the 3 day stay (although not equivalent to a hospital level of care) would still qualify the beneficiary for covered SNF services (CMS, 2015).

Appendix B: Five Dimensions of the Caregiver Reaction Assessment and Scoring Ranges

Self-esteem
(10) Caring makes me feel good
(19) Want to care
(12) Privileged to care
(6) Enjoy caring   **Score ranges:**
(4) Caring is important to me   not applicable all are positive outcomes
(15) Resent having to care (reversed)
(21) Never do enough to repay (reversed)

Disrupted schedule
(14) Eliminated things from schedule   20-25= strong need of intervention
(20) Visit family/friends less   15-19= discussion and follow-up
(7) Stop work to care   11-14= continue to monitor
(16) Constant interruptions   5-10= no need
(1) Activities centered on care

Lack of family support
(13) Others dump caring   20-25= strong need of intervention
(11) Difficult to get help   15-19= discussion and follow-up
(17) Family left me alone   11-14= continue to monitor
(9) Feel abandoned   5-10= no need
(3) Family works together (reversed)

Financial problems
(23) Difficult to pay   12-15= strong need of intervention
(24) Financial strain on family   9-11=discussion and follow-up
(22) Financial resources adequate (reversed)   7-8= continue to monitor
                                             3-6= no need

Health problems
(2) Healthy enough to care (reversed)   16-20= strong need of intervention
(8) Health has gotten worse   12-15= discussion and follow-up
(5) Takes all my physical strength   9-11= continue to monitor
(18) Tired all the time   4-8= no need

Notes: [a]CRA scale version by Nijboer et al. (1999).
CRA question item is represented in parenthesis

Appendix C: Stakeholder/Team Member Evaluation of DNP Project

Problem: Lack of a caregiver assessment tool or policy within the hospice agency.

Purpose: Plan a caregiver respite program that will include policies and procedures that will direct the assessment of the caregiver, determine when to implement respite care, and outline the respite implementation procedure.

Goal: The prevention of caregiver burnout and fatigue

Objective: The creation of policies and procedures that will direct a routine caregiver assessment, the need for respite services and its implementation process within the hospice agency.

Scale: SD=Strongly Disagree D=Disagree U=Uncertain A=Agree SA=Strongly Agree

1=SD 2=D 3=U 4=A 5=SA

1 Was the problem made clear to you in
  the beginning? ____ ____ ____ ____ ____

2 Did the DNP student analyze and synthesize
  the evidence-based literature for the team? ____ ____ ____ ____ ____

3 Was the stated program goal appropriate? ____ ____ ____ ____ ____

4 Was the stated project objective met? ____ ____ ____ ____ ____

5 How would you rate the DNP student's
  leadership throughout the process? ____ ____ ____ ____ ____

6 Were meeting agendas sent out in a timely manner? ____ ____ ____ ____ ____

7 Were meeting minutes submitted in a timely manner? ____ ____ ____ ____ ____

8 Were meetings held to the allotted time frame? ____ ____ ____ ____ ____

9 Would you consider the meetings productive? ____ ____ ____ ____ ____

10 Do you feel that you had input into the process? ____ ____ ____ ____ ____

11 Please comment on areas where you feel the DNP student
   excelled or might learn from your advice/suggestions:

Appendix D: Revised Respite Care Policy and Procedures

Inpatient Care-Respite	Policy# 819
Regulation(s) Standards: 418.108, 418.100(b), 418.100(e), 418.204 GA 290-9-43.16	**Effective Date**: January 2017
	Revision(s) Date: December 1, 2016

Purpose: To establish the criteria for admitting a patient for inpatient respite care.

Policy: In the event that the family of a hospice patient becomes fatigued or when any other situation arises that would be mitigated by the removal of the patient from the home for a short period of time, respite care may be provided. This is offered on an "as needed" basis for a maximum of five (5) consecutive days and the agency assumes the financial responsibilities for this time period for Medicare patients. If the patient/family elects to stay longer than 5 consecutive days, the patient/family will assume financial responsibility for those days. Respite care for the Medicare/ Medicaid benefit patient will be provided directly under contract with a care facility that meets Medicare guidelines for care and the agency assumes the financial responsibility.

For the non-Medicare/Medicaid benefit patient, hospice may assist in coordinating the transfer to another level of care, but does not assume financial responsibility. Hospice personnel will be available 24 hours a day for clinical consultation to the inpatient personnel caring for the hospice patient.

Respite care is at the discretion of the Interdisciplinary Group and must be provided in a participating Medicare/Medicaid facility that provides 24 hour nursing care that will meet the patient's needs, and in accordance with the patient's plan of care.

Procedure:
1. One or both the following events must occur:
   A. The caregiver of the hospice client must undergo evaluation utilizing the Caregiver Reaction Scale assessment tool and express values that indicate fatigue and/or burnout and the hospice Interdisciplinary Group evaluation must reflect a direct need for respite care based on these findings.
   B. The hospice Interdisciplinary Group evaluation, including patient/family must reflect a situation which could be mitigated by placing the patient for a short time in a custodial care setting. This could include, but is not limited to, emergency or medical treatment of the sole caregiver, the caregiver being rendered temporarily physically or mentally unable to provide care, in the absence of the caregiver, or for the safety of the patient.

2. Arrangement with the attending physician, if any, the Medical director and the care facility must be coordinated by the Administrator, nurse or designee.

A. Approval for respite services must be approved by the Medical Director and Administration.

B. The Administrator, social worker, or designee must contact the contracted care facility for bed availability and dates of admission.

C. This information will then be transferred to the primary care nurse, case worker, or designee to inform and prepare the caregiver of patient placement.

D. The Administrator, social worker, designee will then arrange for transportation to the care site if needed.

E. The primary care nurse will administer and read a TB skin test according to policy prior to transfer.

F. The primary care nurse will reconcile any and all medications and update the chart, ensure adequate personal care supplies and a hard copy of the TB skin test results are in the caregivers possession for transfer with the patient, be available to answer any of the caregiver's questions, and provide the receiving care facility nurse with an oral patient report prior to arrival.

G. The caregiver must either accompany the patient or visit the care facility prior to admission to sign the patient's admission forms.

3. Care in the facility will be custodial only and the hospice plan of care will accompany the patient and be followed by the facility staff.

4. A hospice registered nurse will be a liaison between hospice and the care facility.