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Life Review Workbook

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Abstract

The Visiting Nurse Association (VNA) & Hospice is a not for profit organization that provides a wide range of home health care services in the Monterey, San Benito, Santa Cruz and South Santa Clara counties. VNA & Hospice is a specialized sort of care for people facing a terminal disease, their families, and caregivers. VNA Volunteers, who volunteer their time to help others, are an important part of the agency's staff. Caregiver burnout is often the result of devoting considerable time and energy when caring for a loved one that is in hospice, and not allowing oneself to rest. The purpose of this project is to provide hospice patient's, caregivers, and families a life review workbook. The intern was responsible for creating the life review workbook. The workbooks are done in both English and Spanish and available in a physical copy form for families. VNA & Hospice should utilize the life review workbook for current and future patient families.

Keywords: VNA & Hospice, caregiver burnout, life review workbook, hospice patients, elderly

Agency & Communities Served

Visiting Nurse Association & Hospice is an agency that provides a wide range of home health care serving Monterey, San Benito, Santa Cruz, and South Santa Clara counties. The agency brings wellness to the community through traveling health clinic services, intermittent care in patient's homes, key specialty programs, and hospice care for those faced with life-limiting illnesses. VNA & Hospice comprises a broad set of team members who each have their specialty and play a specific role in patient care. They have a volunteer program that offers patient companionship visits and community services. The communities served are patients ranging in ages 41 years and older. More specifically, between 81- 91 plus years of age (Junghans, 2022). The majority of patients are elderly individuals.

The agency has both a mission and vision statement. The mission statement is, "to provide the highest quality health care to residents of the Central Coast by meeting their individual needs in a caring, effective, honorable, and accessible manner." The vision statement reads as follows,

> We transform the care and culture to meet the changing needs of patients, families and caregivers. We achieve positive results every day through quality standards, empowerment, teamwork, and accountability. We are trustworthy, innovative and unique in our clinical programs and customer service. We create a collaborative and respectful working environment recruiting highly skilled professionals while retaining satisfied employees. (VNA & Hospice, 2021)

As a result, the agency's focus is to practice a family-centered approach when working with the families.

Problem Model Background and Literature Review

Caregiver burnout is often the result of devoting considerable time and energy when caring for a loved one that is in hospice, and not allowing oneself to rest. This is common and seen within many families who care for a family member that is at their end of life. In fact, “studies have shown that 60% of caregivers experience symptoms of burnout” (Cleveland Clinic, 2019). Taking the time to care for oneself while caring for a family member can be for reasons such as being the only family member the patient has therefore provides care 24/7, having limited resources which can negatively affect both patient and caregiver, and ultimately affecting the way the caregiver perceives the family member who they are caring for.

Oftentimes, caregivers are not aware that they are experiencing caregiver burnout. Being aware of the following signs and symptoms is necessary to take immediate action and prevent from worsening. Among many, some examples include,

> You neglect your own needs, either because you’re too busy or you don’t care anymore, your life revolves around caregiving, but it gives you little satisfaction, you’re increasingly impatient and irritable with the person you’re caring for, and you feel helpless and hopeless. (Smith, 2023)

If the caregiver is manifesting any form of burnout, it is crucial to reach for help. Addressing the issue could prevent patients from becoming injured, patients feeling isolated or depressed, and ultimately avoid a faster decline in health.

Contributing Factors

A contributing factor for caregiver burnout is when the caregiver is providing 24/7 care for their loved one in hospice. Most caregivers take on the responsibility of caring for their family member because they are the only person who has the time and ability to care for them.

However, this can eventually take a toll on the caregiver. In fact, according to the Cleveland Clinic, caregivers who solely see themselves as primary caregivers experience burnout given it is too much for them (2019). The caregiver may feel guilt when asking for help because they could also be seen as the primary caregiver.

The shortage of respite caregivers is another common cause of caregiver burnout. It is important for the caregiver to have a support system that they can rely on, but at the same time not feel guilty for doing so. According to Smith, it is important to reach out for support from friends and family nearby to support with running errands, providing a hot meal if able, or stepping in to supervise the patient in order to ensure the caregiver receives a proper break (2023). While caregiving may be incredibly gratifying, numerous circumstances might contribute to feelings of overload and stress. Caregivers' physical and emotional weariness might worsen if they do not address it.

Another contributing factor that leads to caregiver burnout is the limited available resources for family members of hospice patients. One major barrier that people face when attempting to access services is cultural competency. Minority families often experience language barriers that inhibit their ability to access much needed services which can result in decreased quality of care. Lacking this skill can be detrimental for both the caregiver and patient. According to Tulane University, “Cultural competence aims to break down barriers that get in the way of patients receiving the care they need. It also strives to ensure improved understanding between patients and their providers” (2021). Cultural competence is significant because it is a mentality and attitude that attempts to comprehend, connect with, and effectively engage with individuals from other cultures. It is critical for maintaining equitable, courteous, and productive relationships in a variety of settings.

The influence of language barriers on healthcare quality is significant. They are widespread between healthcare personnel and patients who do not speak the same language. Effective healthcare relies on patient-provider communication. Language limitations have ramifications for healthcare delivery and patient satisfaction. According to Al Shamshi et al., language barrier research discovered that among patients who did not speak the native language, 66.7% faced a barrier when accessing healthcare, and 20% did not seek healthcare services if these were not readily available for fear of not understanding their healthcare provider (2020). This study shows that language difficulties have an indirect influence on the quality of treatment that patients get. Uneven treatment due to linguistic problems is connected with uneven access to healthcare and unequal health outcomes.

The third contributing factor that leads to caregiver burnout is when the caregiver loses the connection to who their family member was. A term that can be used to best describe this is "*compassion fatigue.*" Compassion fatigue can be defined as "the physical and mental exhaustion and emotional withdrawal experienced by those who care for sick or traumatized people over an extended period of time" (Merriam-Webster, n.d.). According to Cleveland Clinic, compassion fatigue arises when a caregiver bears the emotional stress and trauma of the person under their care. It results in a loss of empathy or a lack of concern for the person in your care, and both compassion fatigue and caregiver burnout can occur concurrently (2019). It is important to recognize when a caregiver is experiencing burnout to avoid leading to compassion fatigue.

Symptoms to look out for when experiencing compassion fatigue include, "Avoidance and not wanting to be around your loved one (choosing to work late, daydreaming about no longer having to care for them, etc.), a decrease in patience and tolerance, feeling overwhelmed, exhausted, and drained, angry outbursts that are uncharacteristic of your behavior," (Bursack, 2022). It is essential for those who are caregiving to be aware of the types of symptoms that can occur to protect the relationship the caregiver has with the family member.

Consequences

One of the consequences from caregiver burnout is the risk of patient injury. It is important for caregivers to be able to recognize the symptoms of burnout to avoid harming both themselves and the member they are caring for. Smith states,

> If the stress of caregiving is left unchecked, it can take a toll on your health, relationships, and state of mind—eventually leading to burnout, a state of emotional, mental, and physical exhaustion. And when you get to that point, both you and the person you're caring for suffer. (2023)

This can be detrimental for individuals and families that suffer the consequences. It plays a domino effect in who has a direct relationship with the patient.

According to Reinhard et al., family members who are receiving care from a caregiver who is experiencing burnout can harm the patient in two ways. The first way is "if caregivers do not have the knowledge and skills to perform their work, they may unintentionally harm their loved one, despite their good intentions and hard work" (n.d.). The second is "caregivers who are at risk of depression while caring for spouses with significant cognitive or physical impairments are more likely to engage in neglect or abusive behaviors, such as screaming and yelling, threatening to abandon or use physical force, withholding food, hitting, or handling roughly" (n.d.). Not only does caregiver burnout negatively affect the caregiver, but the patient can become injured in ways that could be preventable.

A second consequence of caregiver burnout is that patients feel isolated or depressed. Reinhard et al. states that “When caregivers themselves are distressed, burdened, or depressed, they might leave elderly alone for long periods of time, ignore them, or fail to provide any companionship or interaction” (n.d.). This then leads to family members who are not adequately receiving the care they need. This is why it is extremely important to recognize that caregivers are experiencing burnout and reach out to family members or the agency that is offering them services.

Caregiver burnout can also result in neglect of patients. Neglect can show up in a variety of ways (e.g., malnutrition, bed sores, etc.). This is why it is important to consider respite care to avoid harming the patient and leading them to become depressed or isolated. This can be due to “not having a support system to relieve you when you’re tired” (Cleveland Clinic, 2019) and giving caregivers a break. It becomes difficult for a caregiver to care for oneself, much less the patient they are responsible for, when the demands placed on their mind and body become too great. This can result in the increased risk of the patient feeling isolated or depressed.

A third consequence of caregiver burnout is that there may be a faster decline in a patient’s health. Caregiver burnout can be detrimental to the patient as they are directly affected by their caregiver. If a caregiver does not address the underlying issues of what’s causing their burnout, it can cause a negative impact on the patient. The patient can become depressed and ultimately loses hope in their condition. According to the Cleveland Clinic, “If mental health symptoms, such as depression or anxiety, are left untreated, quality of life reduces for both you and your loved one. Your loved one’s well-being can also decline” (2019). It is critical for the caregiver to keep in mind that their loved one is reaching their end of life and giving them the comfort they need is essential. This includes taking care of oneself to better serve their loved one.

Caregiver burnout is a real consequence of long-time care for a family member in hospice. According to Bursack,

> It is up to family caregivers to be their own advocates and implement care plans that allow for regular breaks, self-assessments, respite time, professional and peer support, and changes in workload. Making these changes will not only help to minimize caregiver burden but also allow you to create a more positive and rewarding caregiving experience for you and your loved one. (2022)

This is why it is important to focus on tackling the problem of caregiver burnout to best assist not only the patient but caregiver. When caring for their family member, as a caregiver one must remember that communication is key in voicing when help is needed. If the caregiver has no family to reach out to, contacting the agency is the next step to be taken to assist in their needs.

Contributing Factors	**Problem**	**Consequences**
● Providing 24/7 care for loved ones on hospice	Caregiver burnout	● Patients could be injured
● Limited available resources for family members of hospice patients		● Patients feel isolated and/or depressed
● Caregivers lose the connection to who their family member once was		● Faster decline in health

Project Description

Life Review Workbook

The project was designed to create a life review booklet that can be filled out by a caregiver while caring for their loved one. It focuses on reminding caregivers the reasons why they decided to care for their family member who is in hospice. A goal of this project is to support caregivers in relieving stress and allowing them to make caring for their family members a more memorable experience as they come to the end of their life. The booklet can be filled out collaboratively between the caregiver and patient with the intent of taking some burden off the caregiver. It also allows for other caregivers to spend time with their loved one and utilize the workbook to document notable experiences they had with their patients.

Project Justification

This project is important because it will allow caregivers and their family members to create a life review of the patient who is in hospice. The purpose of this project is to address the most important contributing factor which is that the main cause of caregiver burnout is providing 24/7 care for loved ones who are in hospice. Individuals provide care for others for a variety of reasons, such as a sense of duty or just out of love and concern for the person receiving care. Providing care for a loved one is being aware that although it may be a fulfilling duty, there are stressors that one courageously bears. Among them include conquering several physical obstacles, providing unwavering comfort, and working around the clock. It is tough for the person giving care to prioritize their own needs because being a caregiver is an extremely demanding position. The project will help ease the caregiver burnout symptoms by permitting the patient to share memorable experiences with them.

Benefits

This project is useful because VNA & Hospice can hand out the Life Review workbook to the patients and families they serve. It will give patients and their family an opportunity to share memories and experiences lived, share their wisdom, and provide a sense of closure. Adding onto sharing memories, filling out the workbook together will allow them to reminisce about the memories and can serve as a guide to continue adding more important information about their loved one. Expanding on the closure aspect, this project could open the door for families to share and pass down memories that may have not been shared previously with family members. The life review workbook will be provided in both English and Spanish to benefit the communities that VNA & Hospice serves.

Implementation Plan

The way this project will be implemented is by creating the life review workbook. The idea was first introduced during a meeting with the mentor at VNA & Hospice. The goal was to create a “diary" type memorabilia for families to create more memories, share stories, family traditions, words of wisdom, etc. that can be shared for generations to come. Once the idea was implemented, the next step was to research ways of how to put a life review workbook together. One of the most important things during this process was selecting the questions that were going to be used for the workbook. Once the questions were selected and reworded, the process became easier. The idea was to run a pilot program to get an idea of the turn out. When meeting with the first family and introducing the project, they liked the idea and were on board with it. The same was done with the second family and they too agreed to test it out. After the pilot test was complete, the first draft of the workbook was created. It was shared with the VNA & Hospice mentor and a Medical Social Worker. During a meeting with the mentor, she advised to create a survey that would be sent out to the CEO, COO, Director of Patients Services Hospice, and Medical Social Worker team. A total of five survey questions were created during the meeting and sent out the following day. The purpose for the survey was to receive feedback from the team that works directly with families with hospice patients and what their thoughts were on creating a life review workbook for these families. After this step, the second draft of the workbook was completed. Again, it was shared with the VNA mentor and social worker. Feedback was given by both individuals and changes were made for the final draft. The final draft of the life review workbook was created in both English and Spanish.

Assessment Plan & Expected Outcomes

The expected outcome was to create a Life Review workbook and hand it to two families. They will use this workbook to collect memories and fill out every section along with their family member who is in hospice. The overall goal for the Life Review workbook is to allow families the opportunity to cherish these moments with their loved one. This shared experience will allow families to connect with the caregiver(s) that are sharing these memorable moments with their loved one during the end of life stage. After all, it is a family member who is at the end of life and the connection they can form at this stage would be priceless. The plan was to create a draft and have supporting staff give feedback prior to the final draft. Once the final draft is complete, it will be handed out to families to be filled out.

The expected outcome is for caregivers to cherish this experience with their loved one while writing down oral histories. This is an opportunity to spend quality time with family and enjoy the memories being shared by the family member who is at their end of life. Having a physical copy of a filled out life review of the caregiver’s family member will be a treasure to hold for the following generations.

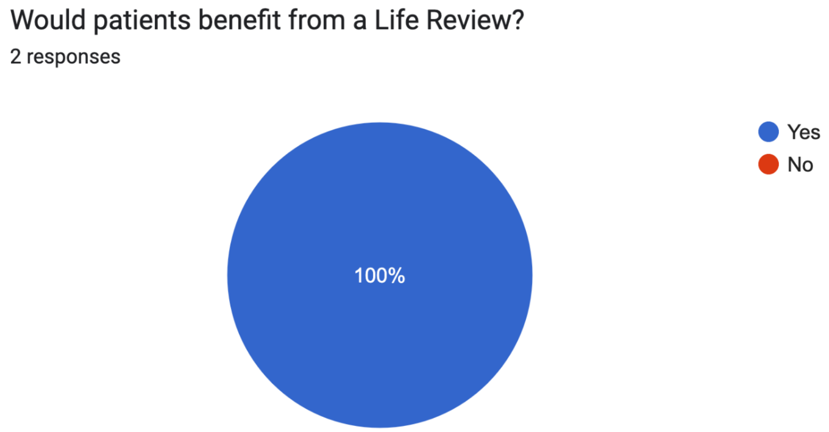
Project Results

The method that was used to gather evidence of the project's success was creating a survey questionnaire that was sent out to the Medical Social Workers at the agency, the CEO, COO, and the Director of Patient Services Hospice. A total of five questions were created that centered around the benefits of delivering a life review workbook for hospice families. Out of the seven people that received the survey, only two responded.

One question asked if patients would benefit from the life review workbook, and both responses were yes. The next question was open ended and asked if all patients would benefit from this project. One response was that patients with dementia and Alzheimer's disease would not benefit, while the other respondent wrote that she believed all patients who were open and wanted to share a life review would benefit from the workbook. Both respondents also agreed that if the patient is not a good historian, then family members could help supply their information for the life review workbook. When responding if a life review is important for patients, both respondents agreed that it will allow them to understand who the patient is, share the life they've lived, and could also be a tool to understand the why's of decisions they've made. Lastly, both respondents agreed that having a physical copy of the life review workbook is preferred over an electronic copy because it allows for an in-person verbal conversation and dialogue.

Although the expected outcome was to receive all seven responses, the two received showed an overall 100% benefit in the project. The reason for not achieving all seven responses was due to the delayed implementation of the survey therefore delaying the overall workbook and having it ready in a timely manner. Initially, there was no intention of delivering the survey.

Later in the project is when the survey was introduced and as a consequence there was not enough time to receive all seven responses and hand out the final draft to families.



Conclusion & Recommendations

This clearly shows the benefits of providing a life review workbook to relieve caregiver burnout. The importance of having the patient who is in hospice to share their experiences with their caregiver and loved ones is a cherishable moment. Through the life review workbook, caregivers and family members can dedicate to providing the highest quality care without feeling overwhelmed or burned out. The patient uses this time to reflect on, assess, and analyze prior events in order to develop a deeper sense of who they are, which they subsequently communicate to those closest to them. The key takeaway here is that the life review workbook gives permission to both the caregiver and patient to provide adequate time for the procedure, taking into account the patient’'s whole existence from conception to the present, and examining and combining their recollections.

Based on the findings and results of the project, it is recommended that VNA & Hospice utilizes the Life Review Workbook and provides a copy to their patients and their families. One thing that could have been done differently would have been to have done the survey a lot sooner rather than last minute, to have had a better response turnaround time. This would have allowed for the workbook to have been completed on time and handed out to families to see their responses to the overall project. Although this was not the case, the agency can still make use of the life review workbook for current and future patients and families.

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Appendix A

Project Implementation Plan

Activities	Deliverables	Timeline/Deadlines	Supporting Staff
Mentor gave the idea for life review workbook	Meeting	Fall 2022	Quinn Junghans
Researched ways to organize ideas	Online	Fall 2022	Quinn Junghans
Designed an outline and questionnaire	Online	December 2022	Quinn Junghans
Partnered with a family to pilot the program	Ivy Park Residence	January-Feb 2023	Quinn Junghans
Partnered with a second family to continue pilot	Pacific Coast Post Acute Center	February- July 2023	Quinn Junghans
1st Draft workbook	VNA & Hospice	October 6, 2023	Quinn Junghans & Linda Rios
Met with mentor and came up with survey questions idea	VNA & Hospice	October 10, 2023	Quinn Junghans
Obtain feedback and revise 1st draft	VNA & Hospice	October 13, 2023	Quinn Junghans & Linda Rios
2nd draft book review	VNA & Hospice	November 13, 2023	Quinn Junghans & Linda Rios
Final draft book review	VNA & Hospice	November 14, 2023	Quinn Junghans & Linda Rios
Handout final draft to families	Ivy Park Residence	November 16, 2023	Quinn Junghans & Linda Rios

Appendix B

Life Review Workbook- English

Life Review Workbook- Spanish