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The Importance of Self-Care for Those Who Have Family Members on Hospice

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Abstract

Many adults find themselves taking care of their elderly parents because they need the assistance due to their age or some type of health-related issue. VNA and Hospice is a nonprofit organization that offers home health care services. VNA focuses on making sure not only the patients' personal needs are being met but also the families. The project was an educational intervention that addressed caregiver burnout and the importance of self-care. Typically, families neglect self-care because they are unaware of support resources, underutilizing the resources available to them or they simply don't understand the value in self-care. Neglecting self-care can result in the patients not receiving the help they need, and the overall health of the caregiver diminishes. The project consisted of a needs assessment created and then administered to participants. The project focused on caregivers and managing stress. The results indicated that the majority of the participants participated in some type of stress relieving activity at least once a week and listening to music was found to be the most therapeutic because it improved their overall mood and was the most effective in reducing their stress levels. Secondly, a flyer was developed for families to utilize tips and ideas for managing stress as needed and that they will pass on the information to others. The flyer was a success and was agreed to be utilized with families of VNA during home visits because caregiver burnout is too common amongst many families and they need as much support as possible.

Keywords: Self-care, caregiver burnout, compassion fatigue, hospice care

Agency & Communities Served

VNA and Hospice is a nonprofit agency that has been around since 1951, and they provide a variety of home health care and hospice services to Monterey, San Benito, Santa Cruz and South Santa Clara counties. VNA places an emphasis on individual patient needs and goals, providing care in an ethical, effective, compassionate and fiscally responsible manner (VNA & Hospice, 2019). Many patients are seen daily in all locations, whether it is in the comfort of their own home, a skilled nursing facility or an assisted living facility. According to the VNA & Hospice Annual Report for 2018 a total of 702 hospice patients were serviced and 738 home visits were made to those receiving palliative care services. They strive to accomplish so much and to help as many people as they can and their mission statement is, “VNA is dedicated to providing the highest quality health care to residents of the Central Coast by meeting their individual needs in a caring, effective, honorable, and accessible manner” (VNA & Hospice, 2019). VNA honors their mission statement by accomplishing so much and by assisting as many people as they can.

VNA & Hospice vision statement is:

- 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, 2019)

All VNA employees dedicate their time to working hard so that they can make the hospice experience an easier transition to a patient's last and final day of life. VNA is present from the beginning and throughout the different points of a patient's life because their goal is to make a patient's every last minute worthwhile and most importantly enjoyable and pain free. The VNA staff includes many nurses, physical therapists, occupational therapists, speech therapists, medical social workers and home health workers and each member offers a specific set of skills.

Nurses oversee the patient's overall health as well as their environment, coordinate care with the other team members and they provide education and support to not only the patient, but their family as well. Physical therapists provide individualized home exercise plans and recommend assisted devices and equipment for around the home. Occupational therapists focus on developing solutions and techniques to further promote independence. Speech Therapists monitor a patient's speech limitations and disorders and focus on improving a patient's memory and thinking. Medical Social Workers advocate for the patient's needs such as their limitations, barriers or concerns they may have. And the home health aides provide, "activities of daily living support, assisted with personal care such as bathing, dental care, using the toilet, dressing and undressing" (VNA & Hospice, 2019).

Problem Description

Families and caregivers of those in hospice are neglecting self-care. Families and caregivers tend to do this because they are not worried about their well being. For many of them

their main concern is their loved one and they go above and beyond to make sure their needs are being met. Many prefer not to focus on themselves because they feel greedy and selfish if they do so and they tend to believe it is unfair if they take time away from focusing on their loved one. According to Family Caregiver Alliance, (2019) family caregivers are also at increased risk for depression and excessive use of alcohol, tobacco, and other drugs. Caregiving takes a huge toll on a person's well being and it can cause a mix of emotions and it can feel overwhelming at times especially if families don't have any help from others.

Caring for loved ones during their last and final days can be difficult and a never ending journey because it's hard to see a family member suffering from an illness or just in pain majority of the time. As caregivers many try their hardest to be strong and to remain hopeful because they don't want their loved one to see them weak and depressed, because it doesn't help their situation.

Contributing Factors

There are many contributing factors that add to this ongoing problem. First off families are unaware of support resources. Many caregivers feel all alone during this time and that they can't reach out to others because they feel it is personal and that it is only right they are the ones to deal with this situation. However, families are under utilizing resources that are available to them in assisting with caregiving. The National Center for Biotechnology Information (NCBI) states:

Family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, and receive little guidance from the formal health care providers.

Nurses and family caregivers rarely agree about specific needs or problems during

hospital admission or discharge, in part because nurses are often unaware of the strengths and weaknesses of both the patient and caregiver. (2001)

Disagreement is common amongst care providers when it comes to a person's care and it can make everything a lot harder because one person may think they know what's best for someone while the other may disagree. During the whole process of all of the decision making it's hard because throughout the many stages of a person's illness it's expected that there are going to be decisions that one must make. In these situations caregivers want what's best for their family and so they try to make the decision for them. At the same time it's not that easy because they feel that they may be making the wrong decision at that point in time.

For example, when it comes to children tending to their parents who may have a terminal illness, sometimes with decision making everything will work out fine and other times things may not go as planned. The reason being is that one child may feel they know their parents better than their sibling does and so they begin to believe they know what is right. This situation is far too common and during times like these when medical decisions can't be made or agreed upon amongst siblings, this is where social workers will come in and intervene. Social workers will then take matters in their own hands and begin the steps of going through the patients documents and figuring out if they had an advance care plan in place.

Advance care planning involves making a plan for future health and personal care should a person lose their decision-making capacity and it captures peoples' values and wishes. It enables them to continue to influence treatment decisions, even when they can no longer actively participate (State of Victoria, 2019).

In the situation where this document is in the patient's medical records, then it would help eliminate so much disagreement and frustration amongst family members.

Another factor to this issue is that families and caregivers don't understand the value in or the reality of practicing self-care. Many don't see a reason in it because they feel they don't have enough time to dedicate to such a thing and that it's not necessary. For some families they feel that the whole situation is such a burden on them and that they don't take everything so seriously but in the end it will begin to affect them negatively. "Growing evidence suggests that caregiving may be deleterious to one's health, necessitating health promotion strategies, such as self-care, to support Family Caregivers (FCs). As such, the role of self-care in maintaining FCs' health needs to be understood and addressed" (Penner, 2018). Caregivers who fail to take care of themselves will find that they are not able to do what they need to do for their family members because they will be too overwhelmed and unsure of what they can do.

Consequences

Lack of self-care for families and caregivers dealing with those on hospice care can potentially bring upon many concerns. Failing to focus on a person's self needs can result in multiple consequences such as: patients are not receiving the help they need (elder neglect/abuse), compassion fatigue and diminishment of caregiver physical health. In some cases patients may not be receiving the proper help they need because they may have some family members who feel burdened and feel that it is not their job to tend to their family members. Being that is the case, for some people it can result in elder abuse or neglect.

Approximately 1 in 10 Americans aged 60+ have experienced some form of elder abuse.

Some estimates range as high as 5 million elders who are abused each year. One study

estimated that only 1 in 14 cases of abuse are reported to authorities. (National Council on Aging, n.d.)

Caregiving for a family member puts a lot of responsibility on a person and it puts a strain on this person's relationship, whether that is with their own spouse or with other family members. "Another big issue is that family members suffer from compassion fatigue. Compassion fatigue is 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, 2019) The reason being is because so much time is dedicated to the loved one that not enough time is dedicated to anyone else. The stress itself results in caregiver burnout and not only physically but mentally as well. They get too overwhelmed and it becomes too much and it makes it difficult to want to show the love and compassionate side of themselves because they are focused on just providing the help and taking care of the tasks and typically their rushed because caregivers have other things to do throughout the day. Whether that's working full time, tending to their own family or just overall living their own life. There are many responsibilities in one's life and so all of that together can make a difference in the type of care they are providing to their family member whether it's because they truly want to or because they feel burdened to do so.

The symptoms of caregiver burnout are similar to the symptoms of stress and depression.

They include:

- Withdrawal from friends, family and other loved ones
- Loss of interest in activities previously enjoyed
- Feeling blue, irritable, hopeless and helpless

- Changes in appetite, weight or both
- Changes in sleep patterns
- Getting sick more often
- Feelings of wanting to hurt yourself or the person for whom you are caring
- Emotional and physical exhaustion
- Irritability (Cleveland Clinic, 2019)

On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience (Family Caregiver Alliance, 2019). However, caregivers can begin to experience a ton of stress throughout this time. Caregivers are more likely to have a chronic illness than are non-caregivers, namely high cholesterol, high blood pressure, and a tendency to be overweight. Studies show that an estimated 46 percent to 59 percent of caregivers are clinically depressed (Family Caregiver Alliance, 2019). Unfortunately, there is such a high percentage of those caregivers who go through their fair share of problems and it can be frustrating. Thankfully, there are many resources that exist for helping those caregivers who are in dire need of a helping hand from anyone that can offer them the support they need.

Problem Model

Contributing Factors	Problem	Consequences
Families are unaware of support resources.	Families and caregivers of those on hospice are neglecting self-care.	Patients are not receiving the help they need (elder neglect/abuse).
Families are under utilizing resources that are available to them in assisting with caregiving.		Compassion fatigue

Families and caregivers don't understand the value in or the reality of practicing self-care.		Caregiver physical health diminishes.
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Capstone Project Description and Justification

This project focused entirely on finding current programs and resources that exist to help families and caregivers promote self-care. The goal was to educate caregivers on the importance of self-care and to help them understand that it is not only for themselves but for their loved ones as well. The first main point was informing families of the consequences of not practicing self-care. And the other point was creating a self-care plan and following through with the plan. These two points are highly important and need to be addressed otherwise they will cause the following consequences: patients will not be receiving the help they need which can result in elder neglect and abuse, strains are placed on relationships and lastly when caregivers are physically and mentally burnt out then they are unable to provide the best care possible for their family member.

Project Purpose

The purpose of this project was to address the main contributing factor which is families are unaware of support resources that currently exist to help them address caregiver burnout. This project included multiple steps in order to address this factor. The first one being that a needs assessment was created and administered to caregivers and families so that feedback can be collected. And then once the feedback was collected, the appropriate list of resources was given to each family member as requested. Providing the correct resources would help to address

and hopefully eliminate the amount of stress on each person who is taking care of someone who has been put on hospice.

Project Justification

A needs assessment was given to forty people. The purpose of the needs assessment was to collect information from individuals that could be analyzed to assess why they identify specific needs to be of utmost importance. A needs assessment is an effective way to support clients because it gives them the opportunity to state what it is they personally are in need of and what are their interests. A needs assessment was used to gather information to further help the agency improve what it is they have to offer. After administering the needs assessment each person had as much time as they needed to address the questions they were being asked. They had the opportunity to explain what it is they are looking for and what kind of help they are needing. As a whole, a list of resources were provided and were specifically identified per each person as best as they can be in order to assist them and their needs. Using the needs assessment helped identify the self-care needs that are not being done. “Some caregivers place unreasonable burdens upon themselves, in part because they see providing care as their exclusive responsibility. Some family members such as siblings, adult children or the patient himself/herself may place unreasonable demands on the caregiver” (Cleveland Clinic, 2019). Being that family members are put in this situation it makes it difficult to focus on themselves because they are so consumed about everyone else's well being and forget about themselves. “Many caregivers cannot recognize when they are suffering burnout and eventually get to the point where they cannot function effectively. They may even become sick themselves” (Cleveland Clinic, 2019). Unfortunately, this is fairly common and many of those who are in this

situation find themselves being overly worked which takes an effect not only on them but their family too.

Project Implementation

This project was conducted over the course of a few months and can be found below in Appendix A where the scope of work lists every single task that was done to accomplish this project. The first step was the development of a needs assessment as seen below in Appendix B. The needs assessment consisted of a few questions which focused on figuring out what types of stress relieving activities people participate in regularly. And another question asked people to state the symptoms they believe they experienced in terms of being burnt out. The expected outcome was to identify what kind of help each family specifically was in need of that would address their self-care needs. The needs assessment was then administered to a total of forty people who have a family member or know of someone who is on hospice. The needs assessment was administered by phone calls for easier convenience for the families and in some cases in person visits were made for those who preferred to speak in person.

After all needs assessments were distributed, the analyzing and collection of the data took place. The next step was to find the most common answer from all of the individuals which determined a general need that needed to be addressed. Once that need was addressed, research was done in order to gather information that could be of great use to the family. An informational flyer was distributed to all who participated within the survey as well as given to others within the community so that they can be informed of the importance of self-care (see Appendix D). After the family had received the resources that they requested, the last and final step was to conduct a follow up on each family to ensure that they had the help that they needed and if they

would be needing any further assistance. Those who supported this project are the coordinator and mentor who are in charge of the volunteer department, they can further assist by continuing to find families who would be interested in receiving a copy of the informational flyer.

Currently at this time large resources such as grants and funding will not be needed to fund this project .

Assessment Plan

Developed a needs assessment and then administered it to various participants. This needs assessment allowed people to address the issues that they are currently dealing with. They had the opportunity to state their problems and where it is that they need the help in order to focus on their own self-care. After the collection of all of the responses and finding the most common response, it was taken and researched in order to address the issue. Once the research was completed an informational flyer was given to those who requested more information on their specific topic for self care activities. The informational flyer focuses on one specific topic and it lists activities that one can participate in for self-care practice and it has facts about the benefits of music in case family members want to do more in depth research on their own. After the informational flyer was given to the family members they were given about two weeks to use the tips and ideas of self-care practice. After the two week period a follow up questionnaire was provided to check how effective the resources were for them and to see how likely they are to use the information again if needed. Families were asked if they view the flyer as beneficial for others who are going through a similar situation of a family member being in hospice and many agreed and as a result the flyer will be distributed as needed to future families.

Expected Outcomes

This project addressed the needs of family members and caregivers. The expected outcome was to provide as many resources as possible to ensure that these individuals were taking care of themselves. Families needed to see the value and importance of self-care because without it, it could result in consequences such as compassion fatigue as well as their own physical health begins to diminish. Another expected outcome was that after being provided the appropriate resources to each person in need, each person would have hopefully utilized them to their advantage and reused them as needed. Hopefully they would have also informed others about the information they received so that they could help others who may be in need and feel overwhelmed by all of the responsibilities they currently have to deal with. The informational flyer would have hopefully helped to remind family members that they need to focus on their own health as well otherwise they won't be able to help their family members with their needs. After families received the information on self-care it was expected that they will show major improvement in their own health and well being over time because they will be practicing various self-care activities to help reduce their stress. Two weeks after the family received the informational flyer with the tips and ideas for reducing stress a follow up phone call for a check in had been made to see the status of the families and how they were currently doing to see if there had been any improvement with their overall well being.

Project Results

This project first started off with a needs assessment that was created and then administered to the participants to determine what it is the patients' families are needing from the organization. After the responses were collected, it became apparent that the first needs

assessment did not provide adequate information because the questions were found to be too open-ended and participants' responses did not provide enough information to assess their needs. So then a second needs assessment was created which provided more quantitative information about the participants knowledge and needs related to self-care. The results from the second needs assessment made it easier to then begin the research of focusing on the tips and ideas as recommendations for self-care practices. The project did meet the requirements because the needs assessment was found to be successful, the results from the needs assessment are available in Appendix C. The first graph represents caregivers who have acknowledged that they do experience caregiver burnout and that they do suffer from a few if not all of the symptoms that identify as experiencing caregiver burnout. And the other graph below represents just how often a caregiver focuses on their own self-care and what activities they are likely to participate in at least once or more a week.

Unfortunately, many self-care activities are of least importance to caregivers because they are so focused on taking care of their family members and are more concerned about their well being than their own. However for those that do participate in some activities to help reduce stress, the majority of those participants stated that listening to music is the most effective and convenient way to change their mood when they are having a bad day. With the results that were collected it then led to finding tips and ideas for the family members to help them realize that they need to allow more time for themselves than they currently have. And with the informational flyer that they were given about stress reducing techniques they were able to utilize those tips and ideas at their convenience. Follow up calls were made two weeks after to check in on personal improvement amongst families. Some families were found to be more

motivated and willing to ask for help from those they knew or they decided to practice some of the self-care tips because they realized they were in need of getting better not only for themselves but for their family members as well. They realized they neglected self-care and they wanted to overall improve their own health so that they could be a better person for their family.

Conclusion & Recommendations

Given the results of this project they were not surprising because caregiver burnout is a real issue and has been around for quite some time. People just fail to speak on the issue especially when they are experiencing it first hand because they view it as not being a big deal even though it has proven to be and for some they are just being in denial of it all which in turn results in them being overwhelmed physically as well as mentally. The flyer that was created will continue to be utilized and implemented by volunteer staff when visiting with families for weekly visits. The project itself is complete and does not have to be continued because no further work is needed however it does have the potential of being bigger if someone were to continue the research on this issue because it can go in many different directions depending on how creative someone is willing to be. VNA and Hospice do have a lot of self-care practices to help manage stress but none specifically focus on music. With that being said this project can lead into the start of something bigger. If anything, more research on music and its health benefits will further help families. Finding or creating easy at home self care activities for families to do would definitely be beneficial for future clients.

Personal Reflection

The project clearly showed that caregiver burnout is a much bigger issue than people tend to believe and it shows just how many are affected by this issue. There are many people who

experience this issue not just those with family members on hospice this issue also applies to people who are taking care of someone with some type of life threatening illness or disability. The project was able to provide VNA & Hospice insight on how to help everyone at the home when they are feeling burnt out. This project makes a huge impact in the agency. It has reminded them the importance of caring for the families as well as the patients in the home. They are strategizing ways in which the Medical Social Workers and Hospice volunteers can provide support and comfort to all involved. They are increasing their volunteer recruitment as well to have more volunteers available to provide respite care for the family and caregivers. Being able to increase the volunteer availability, will allow families to be able to take time for themselves. The tips and ideas I provided for the families with this informational flyer will continue to be utilized by the VNA team. What I learned from the planning and implementation for the project is that things will never go as planned even if you want them to. As for contributions to VNA & Hospice I was able to assist a good percent of the families in helping their overall well being and the work I did will continue to be implemented to help assist future families.

While surveying the families the biggest help was that I took time after the survey was done to sit down and have meaningful conversations with each family. Many have been longing to have that type of interaction, the meetings themselves helped to improve how the families were feeling and with the help of the flyer they were even better. As for challenges the biggest was not having the opportunity to implement the project in person for a lot longer like I wanted to. Due to COVID-19 and the shelter in place I had to speak with families over the phone and for some individuals I noticed they do better in person than over the phone. For some people when I

checked in with them to see how they were doing I felt that they were telling me what I wanted to hear versus how they were actually feeling.

I feel that in person they would have answered more truthfully because they would have been more comfortable in sitting down and having that face to face interaction. But I also took into consideration what's currently going on in the world. People are more stressed than they ever have been and their minds are elsewhere and by me checking in with them I felt that stress from them just by their responses. It's unfortunate that these families who are dealing with family members on hospice but then to deal with the spread of COVID-19 puts even more pressure on the families because they are already taking care of them but now they have to be extra cautious in protecting them from catching the virus.

For future capstone students placed at VNA & Hospice they should highly consider continuing to focus on caregiver burnout especially due to this virus because for many who are current clients their spouses usually ended up becoming clients as well and they continue to use VNA services for themselves. It would be beneficial in not only helping them cope with the loss of their spouse but also about what they are dealing with emotionally due to the pandemic.

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Appendix A

Scope of Work

Activities	Timeline/Deadlines	Supporting Staff
Developed a needs assessment for families and caregivers	November/December 2019	Elizabeth Birruete Quinn Junghans
Distributed needs assessment	December 2019	Elizabeth Birruete Quinn Junghans
Collected and analyzed needs assessment results	January 2020	Elizabeth Birruete
Created a second needs assessment	February 2020	
Distributed needs assessment	February 2020	
Made phone calls to families to survey over the phone	March 2020	Elizabeth Birruete
Made visits with families to survey in person	March 2020	Quinn Junghans
Analyzed needs assessment results and input into google forms to create bar graphs	March 2020	
Researched common responses from survey in order to address the most common need for self care	March/April 2020	Elizabeth Birruete
Created informational flyer for families and caregivers	March/April 2020	Elizabeth Birruete
Distributed flyers to families	April 2020	Elizabeth Birruete
Implemented the tips and ideas to families to test for themselves for two weeks to focus on self care	April 2020	Elizabeth Birruete
Evaluated feedback to determine how effective the informational flyer was in addressing self care	April 2020	Elizabeth Birruete

Appendix B

Managing Stress Survey

The following voluntary survey is used to support a student academic project at California State University Monterey Bay. The intent is to gather information about the impact of caregiver burnout with family caregivers of hospice patients. Responses to this survey are confidential and any information provided cannot be used to identify a participant.

1) As a caregiver and or family member would you say that you experience caregiver burnout? If so, please explain. *Caregiver burnout is defined as a state of physical, emotional and mental exhaustion. It may be accompanied by a change in attitude, from positive and caring to negative and unconcerned. Caregivers who are "burned out" may experience fatigue, stress, anxiety and depression.*

2) Here are some common signs and symptoms of caregiver burnout. Please put a check mark next to all that apply.

- You have much less energy than you once had
- You're constantly exhausted, even after sleeping or taking a break
- You neglect your own needs, either because you're too busy or you don't care
- Your life revolves around care giving, but it gives you little satisfaction
- You have trouble relaxing even when help is available
- You're increasingly impatient and irritable with the person you're caring for
- You feel helpless

3.) Here are some simple ways to relieve stress. Which of these are you more likely to do at least once a week if not more? Check all that apply

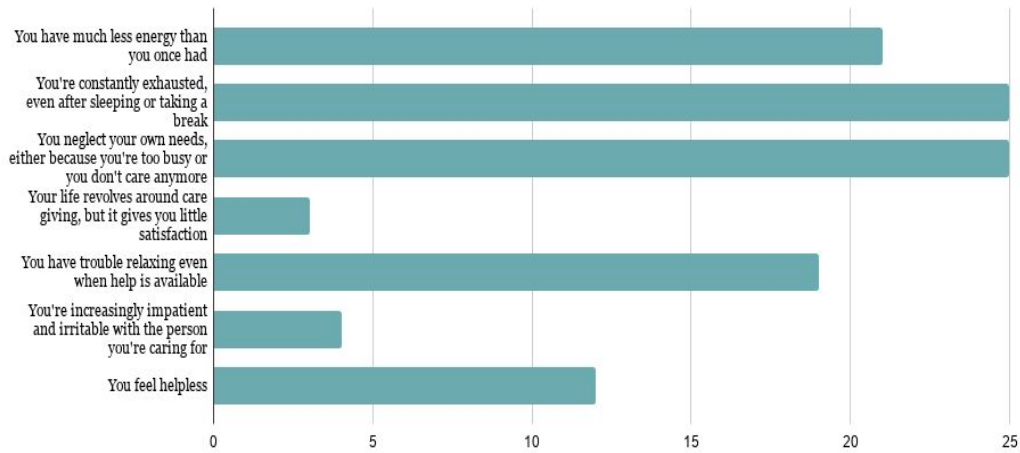
- Listen to music
- Keep a journal
- Take a break
- Meditate
- Paint
- Take a nap
- Ask for help
- Read a book
- Talk to a friend

4.) Are you more likely to attend an outside event to learn more about resources to help with managing stress or would you prefer an informational handout. Please choose one.

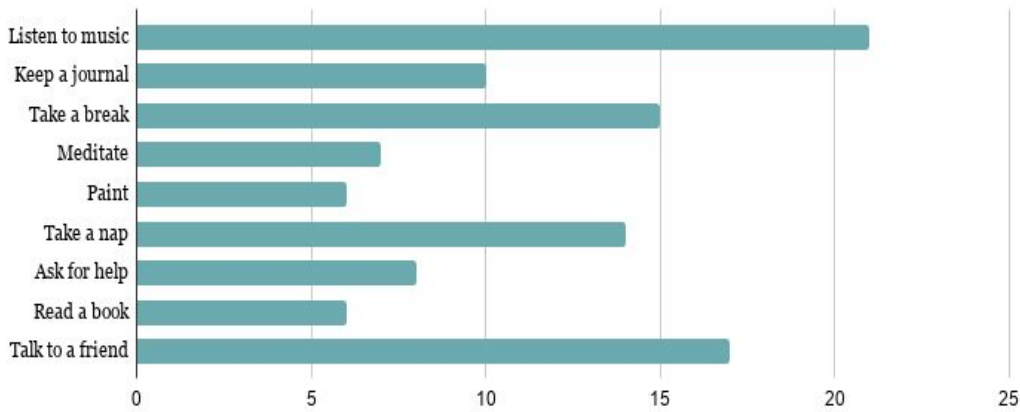
- Yes
- No

Appendix C

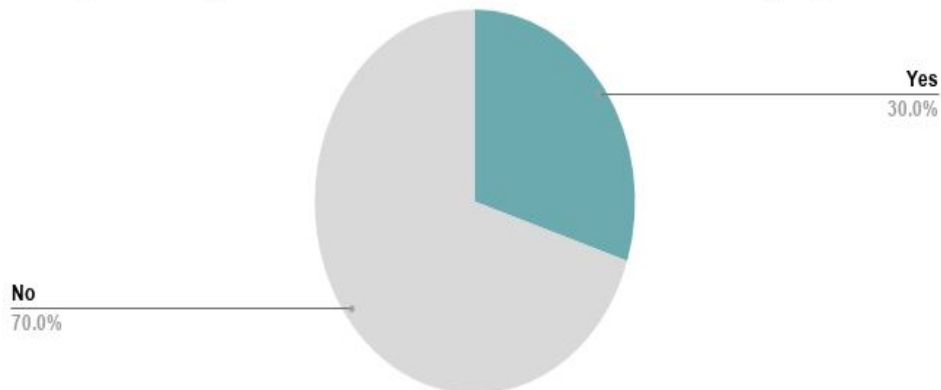
Here are some common signs and symptoms of caregiver burnout.



Here are some simple ways to relieve stress. Which of these are you more likely to do at least once a week if not more?



Are you likely to attend an event to learn about managing stress?



Appendix D

Easy at home activities to do weekly to help reduce stress

- Listen to music
- Journaling
- Walking
- Reading
- Painting
- Meditation
- Sleeping
- Talking to a friend

Tips on how to recover from caregiver burnout

1. Check in with yourself everyday
2. Practice forgiveness & gratitude
3. Learn to accept help
4. Cultivate hobbies as an outlet for stress
5. Join a support group

Some studies suggest that listening to music can have the following positive effects on health

1. Improves Mood
2. Reduce Stress
3. Lessens Anxiety
4. Improves Exercise
5. Improves Memory
6. Eases Pain
7. Provides Comfort

Do you experience caregiver burnout?

1. You have much less energy than you once had.
2. You're constantly exhausted.
3. You neglect your own needs.
4. Your life revolves around caregiving.
5. Friends & family have expressed concerns in your well-being.
6. You have trouble relaxing, even when help is available.
7. You no longer find pleasure in things you once found enjoyable.
8. You feel helpless.

Did you know:

-In the past five years, over 40 million family caregivers provided 37 billion hours of care for loved ones.

-20% of adults are taking care of an older parent

-About 85% of family caregivers in the U.S. don't receive any respite care.

-You can do this. But you can't do this alone.

Caregivers often bring stress upon themselves simply because they won't allow others to pitch in.

- According to a recent survey that was conducted majority of people stated that listening to music helps manage their stress and is the most effective in making them happy.



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