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Hannah Jo Black

hrichardson@murraystate.edu

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Care for Care-Givers
The Importance of Caregivers and the Role They Play

By
Hannah Jo Black

Project submitted in partial fulfillment of the
requirements for the
Bachelor of Integrated Studies Degree

Murray State University
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Foreward

My name is Hannah Jo Black. In April 2013, my father was diagnosed with Omentum Peritoneal Carcinomatosis. To put that plainly, this is a type of cancer that is very aggressive and rare as well. According to WebMD, they state:

It develops in a thin layer of tissue that lines the abdomen. It also covers the uterus, bladder, and rectum.

WebMD also states:

Peritoneal cancer is not the same as intestinal or stomach cancer. Nor is it to be confused with cancers that spread (metastasize) to the peritoneum. Peritoneal cancer starts in the peritoneum, and hence is called primary peritoneal cancer. (n.d.).

Upon my father's first appointment with an oncologist at the respected Vanderbilt University Hospital, we learned that this type of cancer is terminal and almost always non-operable. My father's oncologist stated that any treatment options were merely to "set the clock back" and give us more time. This cancer was aggressive, it was harsh, and it was going to require us to begin round the clock care for my father.

After meeting with the doctor, I was thrust into a world of medical jargon that I did not understand, chemotherapy appointments, post-op surgical care (for comfort purposes) and so much more than what I was not prepared for at 22 years old. I became my father's care-giver and that brought on a whole new group of responsibilities that I had to learn as I went. During the time I was taking care of my father, I was lucky enough to have other support in close family members and friends. However, I reflect on that time and wondered if anyone truly understood

what it meant to be a caregiver and how important they really are. I have become incredibly passionate about the support for caregivers and believe that their care is just as important as the patients. As I reflect on those hard times, I realize that it is incredibly important for caregivers to also remember to care for themselves as well. I understand that a terminal diagnosis for anyone can be life altering and the patient is so important. However, the caregivers are also just as important because they too need support in order to care for their loved one. The purpose of this research is to highlight the importance of caregivers, the incredibly hard demands that they sometimes must meet and how we can better reach them and help them through one of the most difficult times in their life. This is my story, the research I have found and the questions I asked other care-givers. It is imperative that care-givers also receive support as well because they are just as much part of the journey a terminally ill patient is on. With this research, I hope that someone who may find themselves in the same position I was in can find the strength and the resources needed to continue being strong not only for their loved one but for themselves as well.

I would like to dedicate this research paper to my father, David L. Richardson, who fought a long and hard battle with cancer and never lost sight of being kind, compassionate and strong. He faced this disease with courage and grace and a strength that I hope to have someday.

Abstract

Many times, the incredibly difficult role of becoming a caregiver falls onto close family and friends. There is little training for the responsibilities that come along with becoming a caregiver and there is not always support for them outside family or friends.

After much research and interviews with others who had been handed the role as caregiver, it is believed that while there are certain types of communication between caregivers and support groups, there should be better communication of where caregivers can turn to in order to find support. The interviews conducted for the sake of this research showed that while some caregivers who had loved ones sent home on Hospice care did receive resources for help, not all did and not all sought out outside help.

This research was both informative and eye-opening. It showed that there is a bridge to gap in order to help those who are trying to find an avenue for help when they are caring for their sick loved one.

After reviewing the research available, it was concluded that the importance of caregivers and the active role they play is not a well-researched topic. Caregivers are truly unsung heroes in many ways and they may not always have resources made available to them. Reaching out can sometimes be a difficult decision to make and finding a resource that fits their needs can be even more difficult. If more people were aware of how difficult being a caregiver can be and how much it can take to be a caregiver, many people may want to educate themselves more on how they can help a caregiver or how they can help a caregiver seek out resources to benefit them during their journey.

Introduction

What is a caregiver?

A care-giver is *a person who provides direct care (as for children, elderly people, or the chronically ill)*. (Merriam-Webster, 2018). In most cases, the role of care-giver falls onto close family members or friends. This is a task that no person is ever ready for, no matter how “prepared” they think they may be.

While care-givers are incredibly important and resilient in more ways than one, they are human beings. They have basic wants and needs and when they are caring for a sick loved one, those needs may not be met. There is a serious disservice in where care-givers can turn to for assistance. Whether that assistance is financial or emotional, there must be an outlet for someone who needs an emotional break or even a physical one.

It would be incorrect to say that there is no help for those who take on such a heavy role as a care-giver. However, after much research, if a caregiver is not directly asking for assistance or support or direction from a doctor or physician of the patient or loved one, they may not know where to turn at all and they may begin to feel incredibly overwhelmed by their new responsibility as a caregiver. It is imperative that caregivers and physicians speak about what sources are available to them and it is important that caregivers are aware of the people who they can turn to ask for that assistance.

In order for a caregiver to be able to substantially help their sick friend, family or loved-one, they must be able to find ways to support themselves as well. They will likely have to endure a lot of

emotional, physical and financial stress and they may find themselves unsure of where they can turn to for help.

Responsibilities of A Caregiver

To begin, it is important to highlight what some of the responsibilities of a care-giver can be and what is expected of them as well. While researching a basic list of care-giving responsibilities, *Vista Healthcare* gave a list of some of the basic jobs that would need to be accomplished by the care giver. Some of those jobs would include:

- *Personal care of the patient—This involves helping the patient stay clean and comfortable, such as assistance with bathing and going to the bathroom, applying lotion to dry skin, What is Expected of the Primary Caregiver? keeping teeth clean, shaving, washing and combing their hair, providing clean clothes and bed linens and making sure the nails on their hands and feet are trimmed.*
- *Medications—As the primary caregiver, you will make sure the patient has all their prescriptions filled and that correct dosages are given at the proper times. This can include anything from pills to syrups to patches to injections.*
- *Medical care—This could involve cleaning and changing the bandages on pressure ulcers, taking their temperature, applying ice or heat or taking blood pressure readings.*
- *Medical equipment—It is up to the primary caregiver to be well versed in how to use the patient's medical equipment including oxygen machines, wheelchairs, lifts and hospital beds. (n.d.)*

Each of these points are only scratching the surface of what it takes to be a care-giver to a terminally ill patient. It does not take into account the long hours and the sleepless nights, the financial struggle of having to provide transportation to and from doctor's appointments and the lack of emotional support as well for those in this position.

Financial Struggles for Caregivers

As previously mentioned, the financial struggle of caring for a loved one can cause a lot of stress in itself. For example, *Crossroads Hospice* states:

Some financial costs may not be directly linked to the care of a loved one but are present due to caregivers being exhausted or not having enough time to devote to the tasks in their households. Examples of these costs include:

Frequently buying take-out meals due to lack of time and energy

Hiring lawn care maintenance for the caregiver's home

Hiring housekeeping assistance to maintain the caregiver's home

The Cost of Focus for Caregivers

Nearly 1/6th of caregivers work outside of the home at a full-time or part-time position in addition to their caregiving duties. (Crossroads Hospice, n.d.).

Another study shows that care-givers can face more financial struggles because they are unable to work and care for their loved one properly. According to a survey conducted by *Caring.com*,

many care-givers decided to quit working or retire because they were not able to adequately care for their loved one and work at the same time. (Caring.com, 2011). The study continues by asserting,

...42 percent are spending more than \$5,000 a year on caring and over 60 percent are concerned about the impact that providing care is having on their savings, clearly demonstrate that the financial toll of caregiving is a major issue for the millions of Americans who care for their loved ones. (Caring.com, 2011).

In addition to the financial struggle of purchasing basic needs for both their loved one and themselves, care givers may also face the struggle of having to plan and finance their loved ones last wishes and arrangements and to make sure that bills are paid and taken care of. Some of the main financial points for a loved one could be:

- Unpaid hospital bills after the loved one passes
- Funeral arrangements
- Lawyer and attorney fees for any estate/probate help
- Real estate
- Stocks/bonds or life insurance pay outs.

These are all things that must be considered, they can take time to be paid and need to be strategized from the start. Having that conversation with a loved can be difficult but is almost always left up to the care-giver. It is easy to believe that care-givers only deal in the physical and emotional side of their role but the financial struggles are ones that are all too real and forgotten about.

Emotional Struggles for Caregivers

Addition to the financial struggles of care-givers, obviously, there is also the emotional struggles and trials as well. A study called *Emotional Support, Physical Help, and Health of Caregivers of Stroke Survivors* cites several reasons why care-giver's emotional support is important as well as the patient. They maintain that "*Caregivers, no matter what personality, need support and respite from care to be successful in their efforts*". (Steiner, 2008).

With the emotional demands of being a caregiver, it can be incredibly easy to forget about one's own emotional stability because all of the attention and focus has been shifted onto the loved one who is being cared for. However, this type of thinking can lead to emotional distress. In an article by Nancy W. Sheehan and Paul Nuttall, they explain what kind of emotional strife can come along with caregiving. They explain,

Multiple and competing demands on caregivers' time and resources are presumed to lead to high levels of caregiver stress. Negative out-comes, such as depression, anxiety and health problems have been attributed to role overload. (Nuttall, Sheehan 1988, pg. 92).

The emotional rollercoaster of becoming a caregiver can be a constant up and down battle of emotions. They may begin by feeling sad, scared or anxious by the 'unknown' of what is going to happen to their loved one. But along with those feelings can come anger, resentment, fear and guilt as well. It is understandable that a caregiver may feel sad by their loved one's diagnosis and experience fear because they are unsure of what is going to happen to their loved one physically and how it will change their lives. Their anger may stem from not understanding why their loved one was given such a difficult diagnosis and their resentment may stem from the abrupt halt to their life and daily routine and having to trade that in for a new and more complicated one.

Spiritual Struggles for Caregivers

For many caregivers, they may turn to religion as source of comfort not only for themselves but for their love done as well. Spirituality can be a strong force and is often times one of the first things a terminally ill patient may turn to. When a caregiver is caring for a loved one or patient, their spirituality may come into question. They may experience a multitude of feelings and questions as to why something like this is happening to them and to their love one. They may want to know why they were handed such an incredibly overwhelming task like taking care of their loved one, or how they are going to continue and find the strength to do so. However, many who have a strong spirituality may need help finding their strength along the way. Griswold Home Care details what some caregivers have expressed and other spiritual struggles as well.

Why is this happening to my mother...and to my family? Isn't there something we can do? What did we do to deserve this? What is the purpose of this semi-human existence and this long goodbye? How much more of this can we take?

Millions of family caregivers struggle with feelings like these every single day, searching for answers and relief where there often are none. Intangible yet intensely real, this distress can throw caregivers into such chaos that we search for some meaning or explanation that will bring some peace. It takes resilience to carry-on in the face of such adversity. (Meier, 2015).

A caregiver may experience feelings of being 'let down' by God or other higher powers because they have been handed the difficult task of caring for their loved one. They may feel a sense of hopelessness and may not understand where to reach out or where they need to turn. Conflict

may arise about reaching out to a chaplain, preacher, priest, reverend, etc.... because they may not feel like the higher power they choose to worship is listening or has let them down.

Physical Struggles for Caregivers

Along with the financial, emotional and spiritual struggles of being a caregiver, there can also be physical struggles as well. Often times, a caregiver is so focused on the needs of their sick loved one that they often neglect their own physical needs. They may lack the ability to recognize the toll that stress can take on their body because they are hyper focused on keeping their loved one comfortable. The *American Psychological Association* states,

Annual health exams, flu shots and regular visits for health conditions such as high blood pressure and diabetes often get put on hold. Regular exercise and nutritious meals decrease. This puts caregivers at risk for poorer health and worsening health conditions they may already have. (n.d.)

Many times, caregivers are left to do the ‘heavy lifting’ and may find themselves too physically tired to clean or cook for themselves. It may be easier to run through a drive through to get dinner while they are out picking up medicine than it would be to cook a meal at home. As stated above, this could lead to poor nutrition and weight gain.

Caregivers may also be expected to help their loved one with physical activities they may no longer be able to do. For example, if their loved one is not able to physically get in and out of bed, they may have to help their loved one do so. If their loved one can no longer get in and out of their shower or bathtub, their caregiver will have to provide assistance in doing so. This can

take a toll on anyone – even if they are in excellent physical shape when their loved one is first diagnosed.

A caregiver may also lose sleep over caring for their loved one due to different responsibilities. For example, they may have to wake up every couple of hours to administer medication, help their loved one readjust or help their loved one to the bathroom. They may not be able to get an adequate amount of sleep due to the constant up and down with their loved one. According to *WebMD*, lack of sleep can cause a number of different problems such as:

- Heart disease
- Heart attack
- Heart failure
- Irregular heartbeat
- High blood pressure
- Stroke
- Diabetes

(Peri, n.d.).

Caregivers and Compassion Fatigue

As previously stated, a care giver may experience physical effects of being a caregiver. They may forget about their own health and wellness while they are trying to keep their loved one or patient as healthy as can be expected based on their condition. Along with their physical health, caregivers may begin to neglect their emotional needs as well. While trying to provide a caring and safe environment for their patient or loved one, they may begin to experience something

called *Compassion Fatigue*. According to the *American Institute of Stress* , they define compassion fatigue as,

The emotional residue or strain of exposure to working with those suffering from the consequences of traumatic events. It differs from burn-out, but can co-exist. (2017).

Compassion Fatigue is something that can be experienced by anyone who may be working in the caregiving field as a career or someone who is a ‘informal’ caregiver (someone who is caring for a loved one). There are signs and symptoms of what compassion fatigue may look like or what may cause a caregiver to experience it. *The American Institute of Stress* goes on to describes some of the unities of Compassion Fatigue as:

- *Emotional Exhaustion*
- *Reduced sense of personal accomplishment in work*
- *Mental exhaustion*
- *Decreased interactions with others (isolation).*
- *Depersonalization (symptoms disconnected from real causes).*
- *Physical Exhaustion*

(2017).

These symptoms may be widely recognized by many caregivers because of the environment they are constantly in. Their overall priority is to keep their loved one or patient comfortable and happy (to the best of their ability) and that can ultimately begin to create the symptoms listed above for caregivers. It is important that caregivers are able to recognize the symptoms and the best way to handle them. *The Compassion Fatigue Awareness Project* works with helping caregivers recognize what compassion fatigue is and the best way to deal with it. They believe

that the best way to help is by being able to understand what is going on and taking care of yourself as being key. *The Compassion Fatigue Awareness Project (CFAP)* describes the following as being proactive ways to handle compassion fatigue:

- *Be kind to yourself*
- *Enhance your awareness and education*
- *Accept where you are on your path at all times*
- *Understand that those close to you may not be there when you need them most.*
- *Exchange information and feelings with people who can validate you.*
- *Listen to others who are suffering.*
- *Clarify your personal boundaries. What works for you; what doesn't.*
- *Express your needs verbally.*
- *Take positive action to change your environment*

(n.d.)

Recognizing these symptoms and learning how to cope with them is going to be imperative for a caregiver in order for them to continue caring for their patient or loved one.

Caregiver Burnout – What is it?

Along with the physical and emotional stressors of being a caregiver, there is a not-so commonly known side effect of caregiving called *caregiver burnout*. According to *The Cleveland Clinic*,

Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude -- from positive and caring to negative and unconcerned. Burnout can occur when caregivers don't get the help they need, or if they try to do more than they are able -- either physically or financially. (The Cleveland Clinic, n.d.).

It is easy to believe and understand a caregiver experiencing burnout after caring for a loved one – especially if they have no prior experience in being a caregiver. They may feel like their life has been turned upside down and they are thrown into a world that they did not previously know. *The Cleveland Clinic* continues by explaining some of the causes of caregiver burnout. Some of those causes could be:

- Role confusion -- Many people are confused when thrust into the role of caregiver. It can be difficult for a person to separate her role as caregiver from her role as spouse, lover, child, friend, etc.
- Unrealistic expectations -- Many caregivers expect their involvement to have a positive effect on the health and happiness of the patient. This may be unrealistic for patients suffering from a progressive disease, such as Parkinson's or Alzheimer's.
- Lack of control -- Many caregivers become frustrated by a lack of money, resources, and skills to effectively plan, manage, and organize their loved one's care.

- Unreasonable demands -- 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. These individuals also may disregard their own responsibilities and place burdens on the person identified as primary caregiver.
- Other factors -- 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, n.d.).

Caregiver Depression

If you look at the physical effects that caregiver burnout can take on a person, you may find that they are similar to someone who is battling depression. That observation is correct but there are other factors that come into play as well. Caregiver burnout can quickly turn into depression if the signs and symptoms are not dealt with properly. If a caregiver is not able to find some sort of release or relief from the incredibly difficult job of being a caregiver, they may put themselves at risk to falling into a depressed state. According to the *Mayo Clinic*, some of the signs to look for in caregiver depression are:

- Feelings of sadness, tearfulness, emptiness or hopelessness
- Angry outbursts, irritability or frustration, even over small matters
- Loss of interest or pleasure in most or all normal activities, such as sex, hobbies or sports

- Sleep disturbances, including insomnia or sleeping too much
- Tiredness and a lack of energy, so even small tasks take extra effort
- Changes in appetite — often reduced appetite and weight loss, but increased cravings for food and weight gain in some people
- Anxiety, agitation or restlessness
- Slowed thinking, speaking or body movements
- Feelings of worthlessness or guilt, fixating on past failures or blaming yourself for things that aren't your responsibility
- Trouble thinking, concentrating, making decisions and remembering things
- Frequent or recurrent thoughts of death, suicidal thoughts, suicide attempts or suicide
- Unexplained physical problems, such as back pain or headaches

(Mayo Clinic, 2018).

Sadly, depression amongst caregivers has a rising number due to the demands that come with caring for a sick loved one. According to Helen Lavretsky's *Stress and depression in informal family caregivers of patients with Alzheimer's disease*,

The prevalence and incidence of depression in caregivers approaches 40-50% for clinically significant depression, and about 20-25% for major depression. (Lavretsky, 2005).

Caregivers may experience depression without even realizing they are getting to that point.

Social Media and Caregivers

After reviewing the emotional, physical and financial support of what caregivers have to endure, it is important to review how assistance for caregivers can be reached. Social media would be a great place to begin for caregivers looking for help and support. To start, social media is something that many people are a part of. Some of the most popular forms of social media are Facebook, Twitter, Instagram, Facebook Messenger, Pinterest and Snapchat. According to *Statista.com*, there are roughly 168.76 million Facebook app participants, 116.99 million users of the Instagram app, 110.95 users of the Facebook Messenger app, 70.21 using the Twitter app, 58.23 using the Pinterest app and 52.09 using the Snapchat app. (Statista, n.d.). These numbers do not indicate those who do not take advantage of using the app, but it does account for a large percentage of users. Several of these social media outlets could be beneficial for caregivers who are seeking some type of support. According to a survey conducted by *Caring.com*, they stated that 41% of caregivers turn to Facebook, blogs and online support groups. (Graab, 2012) Facebook can be a great tool for those seeking support because they can actively reach out to family member who may not live close by. They can also use this social media outlet as a way to keep friends and family members up to date on their loved one's condition.

Upon further research on Facebook usage and caregivers, *ElderPagesOnline.com* stated the following on caregiver's usage of social media:

According to Pew Internet data, 88% of family caregivers turn to the Internet for information to help with their caregiving. Even if family caregivers are not wearing their caregiver hats when on Facebook (e.g., are more focused on sharing with their friends),

if something very pertinent popped up in their newsfeed or in the side advertising bar, they would likely take notice. (ElderPagesOnline.Com, n.d.).

As stated before, a caregiver may use Facebook as tool to reach out family and friends, but they may also use it as an escape from their day to day activities as a caregiver.

While Instagram is mostly a photo-heavy social media outlet, there is a lot of use of hashtags. Some caregivers may be able to find websites and resources that may be shared under an image with a particular hashtag. Some hashtags are very intricate and specific, and caregivers may be able to find someone else struggling with the same disease as their loved one via these hashtags.

Along with social media, there are other online sources that caregivers can turn to as well. For example, there are online support groups. These support groups can be beneficial for caregivers if they do not feel that a face to face interaction would be comfortable for them. It may also be more beneficial for caregivers who are unable to leave their loved one unattended. Another benefit of online support groups is that someone who is a caregiver may feel more comfortable explaining their situation and their emotions in writing than what they would be able to do in person.

Marketing Towards Caregivers Via Various Social Media

While social media may seem like something everyone would be able to turn to and utilize, sometimes it is not that simple. The overwhelming circumstances of becoming a caregiver does not always lead one to seeking help. They may need someone to guide them in the right

direction. It would be more beneficial if hospitals and doctors were able to give this information to caregivers upon their loved one's diagnosis.

When brainstorming ideas of how hospitals could market towards caregivers needs and wants, they should take the following into consideration:

1. Accessibility
2. Relevance
3. Help

When discussing accessibility for a caregiver, it is important to understand why this is needed.

When someone is caring for a loved one, they may not have the resources to leave their loved one. If a hospital or physician was able to give a caregiver sources and literature beforehand, that would take the pressure from the caregiver having to find support or sources themselves during a difficult time.

Relevance is another important attribute to what hospitals should consider when thinking of how to market towards caregivers. When someone is seeking treatment for a specific disease, a doctor does not just refer someone to a general practitioner. They are sent to a specialist. Why can that not be the case when giving caregivers resources and information. It would be more beneficial to offer a caregiver resources that would meet their needs. If their loved one was diagnosed with terminal breast cancer, it would be best to direct them towards support groups or organizations that are geared towards that illness.

To go along with relevance, offering help could be beneficial for caregivers. Just the act of trying to reach out and ask for help can be very intimidating. Now knowing where to turn or finding a support system that is best fitted to their needs can possibly be overwhelming. If a hospital or

physician is aware of the situation a caregiver's love one is facing, they should be able to make better suggestions on where they can turn to for that support.

When the hospital is trying to market towards helping caregivers, *Aha Media* has a beneficial outline for what hospitals should consider. They take into consideration that caregivers are having to do a number of different jobs while caring for their loved one. They list the following ways would be the most beneficial for caregivers who are seeking support:

Social media: Feeling isolated and overwhelmed, many family caregivers turn to social media for support. Connect with them by offering tips to solve common challenges or moderating online discussions in a condition-specific forum.

Family caregiver blog: Family caregivers lack basic training in this new role. Help them gain important knowledge and skills through expert blog posts on topics such as home safety, avoiding infection, and medication management.

Apps: Help family caregivers stay organized with a free app offering features such as shareable task lists, a calendar to track appointments, daily treatment schedule and medication reminders.

Personal health records: Offer tools to help family caregivers set up, access and maintain their loved ones personal health record. If your PHR platform supports secure patient-physician communication, this is an excellent feature to promote.

(Leibtag, 2015).

Along with the list above an interesting article from *LinkedIn* has the following to say about reaching caregivers via social media. They briefly state,

Facebook is content marketing, not sales. You don't pitch your services (or at least 80% of your posts should not be direct pitches). You offer educational information that captures their interest, reinforces your expertise, and builds brand loyalty. Make a commitment that at least 1-2 updates per week are something that supports family caregivers. (Beauchamp, 2017).

To reiterate, offering educational information could be incredibly useful to a caregiver as they may not know when to reach out or who to reach out to. Offering certain posts that would help a caregiver find help or support could greatly increase marketing and outreach towards caregivers.

Methodology

For this research, interviews were conducted with other caregivers of various ages and backgrounds. Some were caregivers to direct family members like parents or spouses and some were caregivers for in-laws or other relatives. Interviews were also conducted with individuals who worked on the other side of caregiver by working in nursing homes or in-home hospice care. Each interview was unique in its own way as some felt like they were offered adequate support from others – whether it be Hospice care, churches or other resources. Some did not try to reach out to find support other than with their church. For the sake of anonymity, the names of the following interviewees have been changed. Each caregiver was asked a series of questions about their personal experience. Some of the questions that were asked were,

1. How old were they when they began their caregiving experience?
2. How long did they care for their patient/loved one?
3. Did the patient receive care from hospice or other end of life care?
4. Did they seek any outside help?

Each interviewee's experience was different and thus, the questions may have varied based on the experience they had. The interviews that were conducted were done so online via direct messaging with each individual.

Interviews with Care-givers

The first interview that was conducted was with a female (Annie) who was 25 at the time her father was diagnosed with terminal lung cancer. While she was not the primary caregiver for her father, she was very much present and helping in the last few days of his life along with other family members as well. Annie was asked if she was offered any kind of assistance or help in regard to being a caregiver. She mentioned that there were nurses who would come by and check on her father and see if there was anything needed as far as medication went. When asked if she ever felt like she needed someone to talk to about caring for her father, she mentioned that she turned to church and friends in order to cope but did not really seek any outside help outside of that. (Personal Interview – September 7, 2018).

Another interview conducted was with a 39-year-old female (Cathy), who was the caregiver for her mother-in-law who was diagnosed with cancer. She cared for her mother-in-law for one year and two months. Her mother-in-law had hospice care in her home and she felt that she did receive great care from hospice. When asked what kind of care or support she received as a caregiver, she mentioned that hospice offered a Chaplain and the caregivers for hospice also taught her how to change and bathe her mother-in-law if needed. Cathy was also asked if she sought any outside support like in-person support groups or online support groups. She stated

that she asked for support from her church and joined a group there that was offered. (Personal Interview – November 2, 2018).

In my third interview, the individual (Laurie) was a 23-year-old female at the time and while she did not care directly for a family member or friend, she worked in a nursing home facility that was often the ‘end of life’ care for many patients. Her experience was slightly different from the previous interviews. When asked if the nursing home provided any resources to family members such as literature or support groups for the family members, she stated that she was not aware of any resources offered. If they were, it would have been through their human resources. She was also asked if she knew of any of the families reaching out for outside sources for support or help as caregivers. She stated that she did not believe that any of them did. Often times, they depended on the facilities staff for support and care for their loved one. (Personal Interview – November 2, 2018).

In the final interview, a young woman (Lasey) began working as a private caregiver at the age of 22. She is now 29 and still working as a caregiver. When asked if she worked as a private caregiver or if she worked in a nursing home facility, she stated she worked mostly as a private caregiver and only had one patient she worked with at a nursing home. She was then asked if she worked strictly on the medical side of caregiving (such as administering medicine, wound dressings, bathing) or if she had any other tasks such as cleaning the patient’s home, helping with grocery shopping or other household duties. Lasey stated that she did all the tasks. Anything from giving medicine, to cleaning their house, to cooking or also being present if a doctor made a house call. Lasey was asked if any of her patient’s family asked her for any resources for outside help such as support groups or literature on being a caregiver. Lasey stated none of her patient’s family asked for outside help because most of her patients were older (between ages 70-

98) and the family members mostly knew what their prognosis was. (Personal Interview – November 5, 2018).

Caregivers and Asking for Help

The interviews conducted for this research were different in experience but also incredibly informative. Depending on the situation that the patient was in seemed to play a large role in whether or not their caregiver asked for or sought outside help. Many people can agree that sometimes, asking for help can be difficult. Often enough, people believe that they can handle the stress and the work that has to be put in being a caregiver, but the overwhelming enormity of the job can sneak up on you quickly.

A caregiver may not know when the right time to ask for help is. They may think that they have it all under control but while trying to care for their loved one, they themselves may be slipping further and further into conflict and feeling overwhelmed. Per *Amada Senior Care*, some of the signs and feelings that caregivers may experience before or when they ask for help are:

- Depression
- Withdrawal
- Insomnia
- Trouble concentrating
- Anger
- Health issues

- Exhaustion
- Anxiety
- Drinking or smoking
- Altered Eating habits

In many cases, caregivers may not feel it necessary to ask for help. There can be many factors as to why they may not reach out or try to handle things on their own. According to *AgingCare.com*, some care givers may refuse help for the following reasons:

- *The Instinct to Protect*
- *Guilt, the Caregiver's Unwelcome Companion*
- *An Unhealthy Sense of Competition*
- *Stranger Danger*
- *Privacy Issues*
- *Financial Woes*

The Instinct to Protect is a feeling that many caregivers may experience. *Aging Care* states

While many caregivers come to terms with the fact that we can't make our loved ones completely healthy again, we still want to be the person who provides care and safeguards their wellbeing. This protective instinct is powerful and hard to overcome.
(Bursack, 2018).

When a loved one has been diagnosed with an illness that requires round the clock care, a caregiver may feel the need to be their loved one's 'safe guard'. They may feel the overwhelming sense of being the front man to any and all interactions their loved one faces.

Guilt, the Caregiver's Unwelcome Companion from *Aging Care* states,

Many feel that their position as a spouse, adult child or even a parent requires them to personally see to all of their loved one's needs. (Bursack, 2018).

Guilt is a frontrunner in the emotions that a caregiver may feel. The feeling of guilt is strong and while completely normal, it may stand in the way of a caregiver reaching out and asking for help.

An Unhealthy Sense of Competition is another feeling a caregiver may experience according to *Aging Care*. In this portion, they state,

Adult children who are caring for their parents may still be trying to earn the place in their hearts as the one who did the most. Sibling rivalry, even in healthy families, seldom disappears completely. Many caregivers fight to get their family members to help but keep getting denied. (Bursack, 2018).

This is a feeling that has been experienced first hand by many caregivers. From research and personal experience, many times the role of a caregiver falls on a woman in the household or family. According to *CareGiver.org*, “An estimated 66% of caregivers are female.” (2003).

With the statistic of women being the main source of caregiving for family members, it may fall onto the role of a wife, daughter, mother, sister, etc.

Stranger Danger is the next point made by *Aging Care* and it is one that could be completely understandable to recognize. They state,

We often do not trust hired caregivers, whether they are providing care in the home, an assisted living community or a skilled nursing facility. We've heard horror stories and may even personally know others who have had terrible experiences with hired care. We care about our loved ones and have a duty to protect them, so we fear what may happen if we are not present to monitor their care at all times. (Bursack, 2018).

Having a stranger come into your home and trying to help you with tasks as a caregiver could be a welcome relief when one stops to think about it. But it is also a difficult concept to think about too. If a caregiver has been the only source of help their loved one has been around, it may be difficult to allow or even trust someone to come into your/their home and take over a few tasks.

Privacy Issues could also be a reason caregivers may not reach out for help too, according to *Aging Care*. In this section, they state,

Some people lead more private lives by default. They treat their homes as their safe spaces and consider family happenings to be extremely personal. Whether help is coming from a hired caregiver, a fellow churchgoer, a neighbor or a sibling, many caregivers are simply uncomfortable with the idea of opening up their homes and sharing sensitive information with “outsiders.” (Bursack, 2018).

When someone is being cared for, their comfort is something that should be respected and taken seriously. Their private space or their ‘bubble’ may be the one thing that they feel like they can control when they cannot control their health or their diagnosis. Feeling like their privacy may possibly be invaded could lead the patient to refusing their caregiver to allow ‘outsiders’ come in and see them and help out. This adds more stress onto the caregiver because they may not feel like they are ‘allowed’ to let someone else come in and help because they are respecting their loved one’s privacy wishes.

Lastly, *Aging Care* states that *Financial Woes* as another reason caregivers may not seek help. They elaborate by saying,

Our medical system still lacks sufficient features to keep people in their own homes with the assistance of paid help. There are some programs offered through the VA, Medicare

and Medicaid, but coverage is minimal and most people do not qualify. Meanwhile, whatever assets our parents have must be used for their care. When their money is spent down, they can generally go on Medicaid, but the quality of this care may not be what we would have chosen otherwise. Therefore, many families see to the bulk of the responsibilities themselves to avoid spending money on care, but this can be detrimental in many other ways. (Bursack, 2018).

Let's face it – medical care is not cheap. When someone is handed a terminal diagnosis or diagnosed with an illness that may require long-term care, that can start to add up quickly. While insurance and other money may be available, it can still be very costly. Medical supplies, medication, co-pays for doctor's visits, transportation and other normal household expenses can drain a bank account quickly. Finances are not always an easy subject to discuss anyway and when those struggles rear it's ugly head, it can possibly lead to embarrassment as well.

Communication Between Physicians and Caregivers

When it comes to caregiving, it is inevitable that most conversations will be had with doctors and physicians of the loved one being cared for. It is imperative that caregivers are staying in good communication with their loved one's physicians as they are a dominant part of the equation. Sadly, there really is not a lot of information on the importance of communication between caregivers and the physicians of their loved ones. According to one study by *The Journal of Palliative Medicine*, some caregivers reported the following when it came to communication about certain care with their loved ones physicians:

Many family caregivers reported that a physician never told them the patient's illness could not be cured (20.8%), never provided life expectancy (40% of those reportedly told illness was incurable), and never discussed using hospice (32.2%). Caregivers reported the first discussion of the illness being incurable and of hospice as a possibility occurred within 1 month of the patient's death in many cases (23.5% and 41.1%, respectively). In open-ended interviews, however, family caregivers expressed ambivalence about what they wanted to know, and their difficulty comprehending and accepting "bad news" was apparent in both qualitative and quantitative data. (Journal of Palliative Medicine, 2005).

Communicating with a physician could be difficult in some cases because a caregiver may be overwhelmed by the magnitude of their loved one's diagnosis. A caregiver may not feel like they know the right questions to ask and may be hesitant to ask questions if their loved one is present because they do not want to cause them any fear or uncertainty. *The American Heart Association* gives the following tips for caregivers when speaking with their loved one's healthcare provider:

- *When you talk to your healthcare providers, clarify what you hear to be sure that you understand the information or instructions.*
- *Write down your questions before doctor's visits to make sure you get all your topics covered.*
- *Keep records of all that occurs with your loved one. It will help the doctor give better treatment.*

- *Separate anger and frustration about not being able*

to help your loved one from your feelings about the

doctor. Remember, you are both on the same side. (American Heart Association, n.d.).

This is a great check list of things to remember when speaking to a healthcare provider because it can help alleviate some of the stressors that come when visiting the doctor. Just to reiterate, it is important to clarify what a caregiver may hear from the doctor because it can sometimes be an overload of information in one visit. Repeating what the doctor has said could help a caregiver maintain maximum retention of the information. Writing down questions before attending a doctor's visit is also beneficial because it allows you to go over any questions you personally have or your loved one may have as well. This could clear up any questions about medications, side effects, wound or incision care, or questions pertaining to the diagnosis itself. Also stated by the *American Heart Association* was the importance of keeping all records. This is an important suggestion. It is likely that a loved one may meet with several different doctors and possibly at different locations. Keeping a record of who the patient has seen, what medications they received, what procedures they were part of and what the prognosis/diagnosis of a previous doctor gave could help aid the doctor in knowing what treatments may be beneficial for the patient or what treatments have not worked in the past and if a new treatment plan needs to be accessed.

Lastly, the *The American Heart Association* stated the importance of separating anger towards the situation and anger towards the doctor. Sometimes, when a loved one is sick, it is easy and normal to feel anger, frustration and helplessness. These emotions may intensify if the prognosis or diagnosis of the loved one is bleak. Anger or aggressiveness may be directed towards the

doctor because they are the ones who are supposed to ‘fix’ people. However, it is important to remain calm and remember that the doctors are doing what they can to help and that both the doctor and the caregiver have the same end goal – keeping the patient as healthy and comfortable as possible.

Communication Between Caregivers and Patients

One of the most important communications with caregivers is the communication between a caregiver and the patient or loved one. Ultimately, the care giver is the ‘middle-man’ between the patient and the outside world. The caregiver may be the one who communicates with physicians on the patient’s behalf, pays bills for the patient, contacts employers in regards to the patients absence and others.

When researching communication between the patient and the caregiver, interpersonal communication is so important. Having an open and honest policy between the caregiver and the patient is going to make for easier relationships and overall satisfaction from the patient themselves. Some topics can be difficult to discuss between the caregiver and the patient. Especially if the diagnosis does not have a good outcome for the patient. For example, if a patient were diagnosed with cancer (terminal or long-term), having discussions about end of life care, medication or ‘last wishes’ may be a hard pill to swallow for both parties. However, communication is key to keep the patient happy and the caregiver informed.

The study *Open Communication Between Caregivers and Terminally Ill Cancer Patients: The Role of Caregivers' Characteristics and Situational Variables* highlights a great many points of

why communication between the patient and the caregiver may be strained. One example used is the difficulty in discussing death. The study elaborates by saying,

Krant and Johnston (1977) reported that 92% of family members of American cancer patients had thoughts about the possibility of the patient's death, but only 22% discussed this possibility with the patient. A study that assessed communication at the end of life in three European countries revealed that in the last week of life 30% to 40% of patients experienced communication difficulties with their family members (Higginson & Constantini, 2002). Zhang and Siminoff (2003) reported that death and dying was the most difficult issue for family members and patients to discuss at late stages of lung cancer. (Bachner, Carmel. 2009).

Sadly, within this study and all the variables that were included, they stated the following about communication with death and dying:

The level of open communication between caregivers and patients about illness and death was found to be low, indicating substantial communication difficulties between them. (Bachner, Carmel. 2009).

What Caregivers Wish You Knew

When interviewing the caregivers who were both family caregivers or working as private caregivers, one question came to mind. What do caregivers wish others knew? One caregiver who was interviewed was a private caregiver who was hired by a family. This individual stated,

First, the hardest part about it is the fact that most of these people don't want your help.

They are used to doing everything for themselves. So, to have someone come in and wipe

their bottoms - that they don't like...or tell them they can't do something. (Personal Interview – November 5, 2018).

When asking another caregiver who cared for a close family relative, she stated the following about what she wanted people to know about caregiving,

I wish that people knew how hard it was. It isn't just shuttling them back and forth to doctor's appointments and administering medicine. It is also being a shoulder to cry on when the diagnosis is too much to handle. It is holding the trashcan while they get sick and trying to decide if you should call the doctor about a red mark that formed around their surgical wound. It is helping them bathe, helping them get up and down and helping them get dressed and go to the bathroom. It is a lot of information to remember and a lot of decision making as well. Yes, there are rewards too. Caring for someone you love is a special and intimate thing and it takes a lot of trust and respect. But it is hard... it is really, really hard. To watch your loved one become this shell of the person they were and to watch them battle with their mortality and the coulda, shoulda, wouldas', it's difficult because there isn't anything you can say to make the situation right. You just have to be there, be present, reassure them and sometimes, you just have to listen. Sometimes you just have to take that pain and take that hurt for them. After all they are going through, it's the least you can do. (Personal Interview – November 1, 2018).

When a caregiver is in the depths of caring for their loved one, they may find themselves feeling isolated. Even more so, their friends and other family members may not feel like they know what to say. Sometimes, saying something could make them feel like they are over stepping or maybe making matter worse. Or saying nothing may make them feel like they are not doing enough. It truly is the 'rock and a hard place' scenario. So, what should one say to a caregiver? According

to *BrainLine.Org*, there are a few things someone could say to a caregiver that is open-ended. Some of those things they could say are:

“I don’t really know what to say right now, but I’m here if you need me.”

“I hate that you have to go through this.”

“I’ll pick the kids up for you so you can stay at the hospital.”

“I’ve been thinking about you. Would you have time for a visit this week? You name the time and place.”

“You are a great caregiver.” “You’re doing everything you can.”

(Rawlins, 2013).

These responses are great because they are validating and simple. By expressing your concern and reaching out, it lets someone know that they are thought about and they are cared for. In regards to the first response, it is letting the caregiver know that they have someone to talk to if needed but that person is not trying to express that they know what the person is going through. The second response validates that what the caregiver is having to go through is difficult and their friends or family hates to see them going through a difficult time. The third response is a family member or friend offering to help do something for the caregiver which is so important. Many times, someone may ask a care giver “Do you need anything”? Asking for help can be difficult when someone is caring for a loved one and saying no may just feel easier than asking for help. When someone takes initiative to do something, its incredibly helpful. The response asking if there is a time the care giver can step away and sit down with another family member or friend is an important response because it gives the caregiver a chance to step away from the

responsibilities of caring for their loved one and giving them a chance to de-stress and have a sense of normalcy. Finally, the last response is probably the most important of all. Hearing from someone else that you are doing a great job as a care giver and validating what you are doing is the best you can do is so important. That kind of validation gives the caregiver a sense of purpose and can also boost their confidence as well.

Where Do We Go From Here?

We have provided information of what a caregiver is, what their responsibilities are and what kind of mental, physical and emotional stress they may experience during their time as a caregiver. So, where do we go from here? What can we do to help caregivers more and bridge the gap between their needs and wants and helping to provide to those needs and wants?

The first step would be assessing each caregivers specific needs and wants and deciding where those needs might be met. For example, if a caregiver is helping a patient or loved one who was diagnosed with cancer, the hospital or physician may advise the caregiver to research *The American Cancer Society* and offer them contact information for them.

The American Cancer Society offers a number of services for cancer patients and for their family members as well. Per their website, they state,

While most people know us for our research, we do so much more. We attack cancer from every angle. We promote healthy lifestyles to help you prevent cancer. We research cancer and its causes to find more answers and better treatments. We fight for lifesaving policy changes. We provide everything from emotional support to the latest cancer

information for those who have been touched by cancer. And we do it all 24 hours a day, 7 days a week. (American Cancer Society, n.d.).

Some of the services that they provide are:

- *Understanding Diagnosis*
- *Paying for Treatment*
- *Side Effects of Treatment Explanation*
- *Childhood Cancer Information*
- *Care for Caregivers and Family of Cancer Patients*
- *End of Life care and resources*

(American Cancer Society, n.d.).

All of these resources could help take a lot of stress off the shoulders of a caregiver who may not know where to start. *The American Cancer Society's* website is easy to navigate and even if the hospital only provided their toll-free number and their website, it is one step in the right direction to helping a caregiver of a cancer patient.

Secondly, if a patient is diagnosed with something like *Alzheimer's*, their physician could direct them towards the *Alzheimer's Association*. Per their website, they state,

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. (Alzheimer's Association, n.d.).

This organization works with patients and caregivers as well by offering understanding, resources and support that may be needed after an Alzheimer's diagnosis. Some of the services they offer for patients and caregivers are:

- Care Options: Deciding on care can be a tough decision. We have information to help.
- Stages and Behaviors: Learn about what to expect and what resources are available for each stage of Alzheimer's disease.
- Caregiver Health: The best thing you can do for the person you are caring for is stay physically and emotionally strong.
- Daily Care: A person with dementia will eventually need assistance with daily living. Routines and activities can be adapted as needs change.
- Support Groups: Support groups create a safe, confidential and supportive environment. Find a support group near you.

and much more information. (Alzheimer's Association, n.d.).

If a doctor believes that the patient or caregiver may need help in any of the areas listed, they could extend the same information as they would to a cancer patient but with the Alzheimer's Association. They could offer their patient or their caregiver a checklist of what resources they may need/want and then based off that checklist, they could provide those resources to the patient.

If the caregiver is taking care of someone with a long term illness like cerebral palsy, diabetes, mental illness or epilepsy, the caregiver might find it beneficial to speak to the doctor about their concerns and lay out a plan of where they may find resources and support. For example, many

times a Social Worker would be able to provide these resources or the Human Resources department of a hospital may also be able to provide that information as well. It is of the utmost importance that a doctor takes the time to consider the health of the caregiver as well as they are the ones who are predominately caring for the patient or their loved one.

Conclusion

In conclusion, it is important to reiterate the importance of caregivers and the incredibly hard job they have in front of them when caring for a sick loved one. They are propelled into a world of learning medical jargon, medical equipment, doctors' appointments, personal care for their loved one and emotionally supporting their loved one as they fight whatever medical journey they are on. It is imperative that caregivers not only take care of their loved one but also take of themselves as well. Bridging the gap of reaching out for help and finding resources suited to each caregivers' needs is/are so important and a crucial role in making sure they still care for themselves as well.

Sadly, there is not a lot of research in regards to the importance of caregivers and the important role that they play. Over the course of this research, there was some research found in regards to caregivers and children with behavioral problems but none that could be related for the purpose of this paper. There is an ample amount of what a caregiver may experience during their own personal experience. As previously discussed, their physical, mental, emotional and spiritual well-being has been researched and discussed but the importance of the work they are doing is lacking. Also, the communication between caregivers and the readily available resources to them is lacking as well. While there are resources available to caregivers, their access to it may not always be an easy thing to come by. Per one of the interviews, some caregivers who go home on hospice may be able to access resources better because they are already working with in-home care and a organization. Those who are caregiving for someone who is not sent home on hospice may be left to find that information on their own and that can be an overwhelming experience.

Being a caretaker is not easy. It takes a lot of time, effort, energy and can be mentally, physically and emotionally draining. As previously mentioned, if doctors and caregivers can keep good communication, the caregiver may be more comfortable with expressing their needs and wants and their desire for help. Doctors need to be able to point caregivers in the right direction as to where they may be able to access that information or who can help them access that information. If caregivers and their patients or loved ones can keep open and honest communication, research has shown that it can help alleviate some stress and anxiety open the floor for better communication.

And lastly, if caregivers can remember that what they are doing is a difficult and incredibly selfless job and that sometimes they may need help, they will be better able to help their patient or loved one. Being a caregiver is not something to be taken lightly but it is also not something that has to be done alone. Communication is key and communication is necessary.

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