

# Caregivers of People with Cancer

## The Need for Immediate Information Concerning the Caregiver Role

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### Abstract

The purpose of this narrative review is to continue to illuminate the disconnect experienced by caregivers with the various tasks involved in being a caregiver of a person with cancer. According to White and McBurney (2013), a narrative review involves a person telling a story first hand. The reader will hear directly from the participant in the narrative. Green et al. (2006) noted that narrative reviews written with a specific opinion can be considered commentaries, and the bias of the writer is apparent. Burns et al. (1993) noted that results from research have indicated that caregiver strain for people caring for individuals with cancer is predictable. The predictable symptoms of caregiver strain include feelings of anxiety, confusion, and isolation. Onega (2018) reported that the stress experienced by the caregiver will most likely hinder the care provided to the person with cancer. Northouse et al. (2010), and Ferrell and Wittenberg (2017) have well documented both the unmet needs of the caregiver and the lack of preparation provided for the caregiver of a person with cancer. Indeed, the literature indicated confusion among medical personnel concerning who is to inform the caregiver of the tasks involved in their role (Deshields et al., 2022). The writer invites discussion concerning applying the principles of Universal Design, developed by Dr. Ronald Mace in 1985, to the information and communication systems in the hospital setting. Easier access to educational material involved with caregiving may improve the caregiver's self-reliance.

*Keywords:* cancer, informal caregivers, assistive technology

### Introduction and Purpose

A diagnosis of cancer is devastating not only for the person with cancer, but also for those who are family members and friends. Shock, denial, anxiety, and fear are some of the extreme emotions experienced by all. Many people who become caregivers of those family/friends who have cancer, may seek information immediately and/or later during the medical interventions experienced by the person with cancer. Many caregivers struggle to obtain supportive information or directions (Deshields et al., 2022).

The purpose of this study is to illuminate the disconnect experienced by caregivers with the various tasks involved in being a caregiver of a person with cancer. Information concerning the basic characteristics of caregivers of people with cancer will be explored. Research has indicated how unprepared caregivers are for caring for a person with cancer. Because most family members/friends become caregivers by default, informing the caregiver of the possible tasks of caregiving during the first 10 days of treatment is ideal. The writer developed a survey, which may be informative for the caregiver, presented in appendix A.

The concepts of Universal Design are presented for creating an environment to advise caregivers about the tasks involved in caring for people with cancer. Assistive technologies, which can be applied to various universally designed environments, are presented in anticipating a reduction in caregiver strain.

## **Methodology**

The study presented follows a narrative review methodology. White and McBurney (2013) described a narrative review as involving a person telling a story first hand. The reader will hear directly from the participant in the narrative. Green et al. (2006) commented that narrative reviews written with a specific opinion and the bias of the writer is apparent. The writer is currently a surviving cancer patient. The writer had four female caregivers.

Sources for this review included MEDLINE, Alternative Health Watch, Cinahl, Health Source, Psychology and Behavioral Sciences, Vocational & Career Collection, all on EBSCO. MEDLINE Plus and PubMed from NIH. Dissertations and Theses from ProQuest and Healthfinder from the Government. Websites explored included National Cancer Institute, American Cancer Society, AARP (American Association for Retired Persons). The writer's personal story is noted.

## **Description of Caregivers**

Research has indicated that most caregivers are members of the family and considered an informal caregiver who is not paid. Research indicated that most caregivers become caregivers by default (Ferrell and Wittenberg, 2017). In 2019, The National Cancer Institute reported that most caregivers are female, aged 55 or above. The writer's caregivers were childhood friends, highly educated, all experiencing age-related health issues of their own, all were 60+ years old, and female.

Although the writer's caregivers did not have noticeable disabilities, Okoro et al. (2016) using the 2016 Behavioral Risk Factor Surveillance System data, established that 6 types of disabilities are prevalent among adults: (a) hearing, (b) vision, (c) cognition, (d) mobility, (e) self-care, and (f) independent living. These disability types are more common among adults 65 years of age or older, more commonly reported by women, and by those of non-Hispanic descent. Thus, it is very possible that those who suddenly find themselves in a caregiver role have a functional limitation. All disability types were reported by women more than men-except hearing- more men reported hearing as a difficulty. Impairment with self-care tasks was reported by both men and women. The caregiver herself may be in need of support concerning her own basic needs.

Moorman and Macdonald (2012) researched using the term "grey market" to describe the caregivers without any specific training, yet providing complex nursing care and receiving payment. Most caregivers in this study were considered informal and unpaid. Moorman and Macdonald (2012) were analyzing the physical and emotional strain on both types of caregivers regarding medically complex care such as attending to feeding tubes, colostomies, pressure sores. Those caregivers attending fewer complex tasks reported less caregiver strain. Among the paid, formal caregivers, the more complex the task, the greater the strain. Some of the caregivers providing medically complex care had less than a high school education.

Moorman and Macdonald (2012) also reported that most of the caregivers were female, with an average age of 45. The majority of the participants were white followed by Hispanic and Black. Most of the informal caregivers had earned a high school diploma or beyond. Deshields et al. (2022) reported that female caregivers were 76% of their studied population. The average age was 50 with a range of ages of 18 to 93 years old. Desheilds et al. also reported that with the caregivers who earned 16 years of education, 50% worked full time with private insurance.

Ferrell and Wittenberg (2017) reviewed the random clinical trials on family caregivers of adult patients with cancer. The review followed the protocol of Northouse et al. (2010). Ferrell and Wittenberg (2017) reported that upon discharge from the hospital, family caregivers were unprepared and ill-informed concerning the medical tasks and needs of the person with cancer.

Ferrell and Wittenberg (2017) commented that informational interventions for caregivers may last from 3 hours to less than 20 minutes. The majority of interventions were face to face or with phone calls. However, the primary form of intervention was printed material such as workbooks. The writer was handed a workbook by a nurse. No informative discussion occurred. My caregivers were referred to the Internet for Website information. For many caregivers, navigating the Internet is a challenge. Ferrell and Wittenberg (2017) noted the interventions with caregivers and/or the person with cancer were supposedly conducted by a mental health professional. However the interventions were primarily by nurses. Ferrell and Wittenberg (2017) further noted that caregivers were primarily spouses, white, females with an average age of 55.

### **Unprepared and Caregiver Strain**

From the research previously noted (Deshields et al., 2022; Ferrell & Wittenberg 2017; Moorman & Macdonald, 2012), women, by default, become the informal caregiver for a family member who has cancer. These informal caregivers have, on average, a high school education. Therefore, it may be anticipated that informal caregivers would have difficulty comprehending what tasks are involved to care for the person with cancer.

Several researchers (Northouse et al., 2010; Sklenarova et al., 2014; Yang et al., 2021) along with those researchers previously mentioned, have highlighted that the lack of knowledge provided to caregivers results in the caregiver being ill-prepared for the role. A caregiver giving advice to new caregivers stated to “get as much information as possible before you leave that hospital” (Scott & Arslanian-Engoren 2005).

The American Cancer Society (2007) noted that informal caregivers do not know what questions to ask, or where to go for information. Informal caregivers need to develop communication skills, negotiating skills, and self-advocacy skills. Caregivers may struggle to acknowledge that they are not able to perform some of the caregiver tasks.

Badr et al. (2014) and others (Papastavrou et al., 2009; Sklenarova et al., 2015; Yang et al., 2021) acknowledged that not having the information or ability to care for a family member with cancer, the caregiver may develop symptoms of distress, anxiety, and depression. The American Psychological Association updated in 2020 a list of common caregiver unmet needs such as

interrupted sleep, fatigue, difficulty making decisions or holding one's attention and memory. Secondary needs included employment concerns, financial stress, and less time for self-care activities. Manir and Ghosh (2019) added unmet needs of physical strain, changes to personal and family plans, and upsetting to see a loved one so ill.

Caregiver burden was defined by Liu et al. (2020) as a multifaceted strain, a conflict of multiple responsibilities from caring for someone over time. Liu et al. highlighted that caregiving strain, caregiver burden, caregiver role strain, all have similar definitions. Onega (2018) emphasized that the decrease in wellbeing is a result of providing prolonged care. Caregiving strain impedes the unmet needs of both the caregiver and the person receiving care.

Of most significance, researchers (Deshields et al., 2022; Onega, 2018; Porter, 2012), noted that the wellbeing of the caregiver is directly related to the wellbeing of the person with cancer. If the caregiver is overwhelmed, then the care provided to the family member with cancer will be jeopardized. Yet Ferrell and Wittenberg (2017), reported that informal caregivers continue to be unprepared for the tasks of caregiving for a person with cancer. The writer's caregivers were highly educated and asked doctors directly about care tasks. Often, all four of the caregivers attended doctor appointments with the writer.

Another paramount conclusion to note, Burns et al. (1993) stated the caregiver role strain is a family phenomenon that can be predicted. The emotional, physical, mental, and financial struggles of the caregiver and the family can be anticipated.

It seems apparent that the most important research conclusions thus far are that if the caregiver is overwhelmed, then the care provided to the person with cancer will be jeopardized. In addition, the strain and burden on the role of caregiver can be predicted. If the strain, the anxiety, and the stress of caregiving can be predicted, then it should be imperative to inform caregivers about the tasks of caregiving within the first 5-10 days after diagnosis and/or the beginning of treatment. Even though this intentional and early intervention may not alleviate caregiver strain, the early intervention may at least allow the caregiver to distinguish what tasks can be independently completed and those that cannot.

Many assessments have been developed primarily to measure the caregiver strain associated with dementia or with mental health needs. Some of these measures have been adapted to access the strain level from caregiving associated with cancer (Robinson 1983; Zarit et al., 1980).

Unfortunately, most measures of caregiver strain, burden or role strain have been administered to caregivers late into cancer treatment or after the necessity of their role as caregiver (Deshields et al., 2022; Manir and Ghosh, 2019; Yang et al., 2021). Based on the research obtained and the need highlighted, more assessments and caregiving curricula will be developed to be applied in oncology.

### **eHealth Literacy**

Medical professionals have attempted to encourage the caregiver's comprehension of health terminology related to their family member's diagnosis and treatment. Researchers have developed

computer software programs to enhance the caregiver's means of learning the tasks involved in caregiving. However, several of the programs required an understanding of complex processes, including Wi Fi connectivity and the terminology related to computers, cell phone apps, and the Internet (Badr et al., 2016; Shin et al., 2018; Yuen et al., 2014). The expense of some of the programs and devices are too expensive for some families. Yet some devices, such as the Home Aide program from AARP's Project Catalyst was inexpensive and useful. Home Aide addressed the emotional decision making involved in hiring a home health aide (Project Catalyst and HITLAB, 2017).

Shin et al. (2018) reviewed health technology interventions and readily noted the development of Bright IDEAS, an acronym for Identify the problem, Determine the options, Evaluate options and choose the best, Act, and See if it worked. Bright IDEAS is a problem solving technology for parents, the caregivers of children with cancer.

Badr et al. (2016) developed a Computer Assisted oral cancer REhabilitation and Support (CARES). Interactive health communication technologies (IHCT) have been used to improve patient self-management of care. Badr et al. desired to develop a web-based intervention to improve survivor and caregiver quality of life. A barrier noted within the study for some participants was that they did not use computers.

Keenan (2022) interviewed over a thousand adult caregivers concerning their use of technology in the caregiving role. Caregivers younger than 50 years old indicated that they used the Internet to search for community resources, make grocery orders, and contact the pharmacy. Those participants over 65 indicated a less level of comfort with technology and, in fact, did not use technology.

Yuen et al. (2014) defined caregiver eHealth or health literacy to include the caregiver's resources/strengths to participate in decisions made concerning the care recipient. Emphasized was the need for communication skills as the new 82 item Health Literacy of Caregivers Scale-Cancer (HLCS-C) was developed. To add to the efficacy of this scale was the application of the Flesch Reading Ease and the Flesch-Kincaid Grade Level formulas via Microsoft Word. These applications enhance the readability of the sentence/item by simplifying the length of sentences and the complexity of words. Researchers conducted "cognitive interviews" which allowed researchers and caregivers to determine if each were interpreting the vocabulary similarly. Improving caregiver and patient health literacy is valuable in cancer care. Matching the reading level of the caregiver with the information presented should be required.

### **Internet Resources for the Caregivers of People with Cancer**

Many resources for caregivers of people with cancer share valuable knowledge and guidance for caregivers. The Resources for Enhancing All Caregivers Health (REACH) program associated with the Veteran's Association and the Family Caregiving Program with the American Association of Retired Persons (AARP) answers many questions a caregiver and family members may have regarding the tasks of caregiving (<https://www.AARP.org>; <https://www.REACH.va.gov>). REACH offers information concerning many illnesses a veteran may experience. Overall, REACH focuses

on caregivers of veterans with dementia. REACH shares links with AARP so the user can connect with both websites.

The American Cancer Society (<https://www.cancer.org>) website offers helpful information with direct questions. Though the questions may be considered blunt, the goal is to encourage the individual to contemplate the role of caregiver. Powerful questions including “What if you don’t want to be a caregiver?” “What does a caregiver do?” and “What does it feel like to be a caregiver?” The informational responses to these questions have great capacity bring empathy to a caregiver.

The National Cancer Institute (<https://www.cancer.gov>) website also contains information for the caregiver to consider. Though direct, the questions are intended to prepare the caregiver for possible reactions from family or friends. “Be prepared for some people not to help.” Reasons for not helping a caregiver could be that an individual does not want to be involved in order to avoid emotional pain.

All of these organizations offer access to supportive information via social media including online chat, one-to-one visual and voice conferences, and training/teaching videos using YouTube. Many organizations offer resources in Spanish and Chinese.

The information found on many websites concerning cancer and caregiving are compressed and could be considered dense. The amount of information could be overwhelming to a caregiver who is over 65 years of age. The number of clicks used to find the information regarding caregiving may be confusing as well. The font size may be too small for those with visual decline, and the caregiver may not have the computer skills to correct the issue. Closed Captioning may not be available on YouTube videos to allow a person with hearing loss to benefit. And finally, the level of vocabulary may be too challenging to the caregiver.

### **The Application of the Principles of Universal Design**

The application of the principles of Universal Design (UD) appears appropriate for removing barriers, indeed creating an environment for caregivers to access information concerning the tasks of caregiving.

The concept of Universal Design (UD) was developed and then published in 1985 by Ronald Mace, a professor at North Carolina State University. Dr. Mace focused on access to products and the environment for all individuals; however, Dr. Mace emphasized access particularly for people with disabilities (<https://udinstitute.org>). Dr. Mace’s seven principles of UD are (a) equitable use, (b) flexibility in use, (c) simple and intuitive, (d) perceptible information, (e) tolerance for error, (f) low physical effort, and (g) size and space for all to approach and use (<https://www.udinstitute.org>).

### **Universal Design Examples**

Consider the use and/or access to computers, cell phones, apps, software, the Internet, or a website for an informal caregiver of a person with cancer.

1. Equitability ensures that all individuals would have access to the environmental area or device. Indeed, the products should be attractive and pursued by all.
2. The flexibility of a product would reassure individuals working at a comfortable pace and making their own decisions is favorable. No penalty should occur for an individual working independently.
3. Promoting simplicity and the user's intuition, especially when accessing a website, is obviously needed for all participants to obtain information more easily. Enhancing a user's ability to read or hear directions from the website is also needed. Increasing the font size when needed should be easy to achieve.
4. The names and terms pertaining to computer parts should be perceptible and distinguishable. The instructions should be observable/audible to maneuver within the environment or the device. Instead of words, using pictures and/or graphs would be helpful to all users. Selecting a comfortable reading level for all users would enhance following the instructions.
5. The term "user friendly" applies to all individuals. People should be able to make mistakes and recover easily to avoid becoming frustrated. Using Speech to Text and/or Text to Speech software should be available for those with low-vision. Closed Captioning would be helpful to those with hearing impairments.
6. Minimizing the number of clicks or links used to find desired information collaborates with other principles to highlight feeling comfortable within the environment or using the device.
7. Creating an environment around the use of a device, as well as the software within the device, all individuals should have a clear view of all items and elements pertaining to the information sought. The size and the space needed for access should be comfortable for all.

Recalling Yuen's et al. (2014) application of the Flesch Reading Ease and the Flesch-Kincaid Grade Level formulas via Microsoft Word is an excellent example of making information understandable. Indeed, Microsoft offers Closed Captioning and content enhancements. However, for those 65 years old and older, attention must be given to the caregiver's comprehension and memory complications, communication and visual difficulties.

### **Assistive Technology Tools**

Several assistive technology tools are available for a reasonable cost, especially for hospital corporations and insurance entities. Applying the principles of Universal Design to technical/electrical devices would promote the ADA requirements for those organizations that receive federal or grant funding.

### **High, Middle, and Low Assistive Technology Tools**

Information gathered from the Center for Inclusive Design and Innovation at Georgia Tech University (<https://www.cidi.gatech.edu>) described high level assistive devices as power/electronic wheelchairs and digi-drive technology to drive a vehicle. High level tools also include software for screen readers, text to speech, and screen magnification. Specific keyboard designs such as touch screen, and one-handed are also considered high level tools. The Center for Disability Studies at the University of Hawaii noted that mid-level assistive technology tools



included books on CDs, manual wheelchair, alternative mouse, and Closed Captioning. Low level assistive devices include handheld magnifiers, large, printed text, canes and walkers, and a lever door pull (<https://www.ist.hawaii.edu>).

### **Specific Assistive Technology Devices**

Freedom Scientific (<https://www.freedomscientific.com>) advertises several types of software and devices for those with low-vision issues on their website. Job Access With Speech, commonly referred to as JAWS, is a screen reader with a speech synthesizer and/or a braille display. Freedom Scientific's website describes OpenBook as a software that changes printed documents or graphs into text to a computer. OpenBook can use the camera PEARL, an acronym for "process and experiment automation real-time language." PEARL offers human-sounding voices as it reads material in real-time.

For people with hearing impairments, the Minnesota Department of Human Services-Deaf and Hard of Hearing Service Division (<https://www.mn.gov/deaf-hard-of-hearing>) describes the 5 most common devices for people with hearing difficulties: (a) an audio induction loop, (b) a FM system, (c) an infrared system, (d) a personal amplified system, and (e) Bluetooth systems. Audio induction loop is portable and eliminates background noise. The FM system transmits sound via radio waves. The user wears a headphone, neckloop, or other devices. An infrared system transmits sound using invisible light beams. This device is used only inside. A personal amplified system simply transmits sound via a microphone, earphone or neck loop. The Bluetooth system uses Wi-Fi to transmit sound. Individuals can use a smartphone or tablet with earphones to connect.

There are many companies manufacturing helpful assistive technology devices. Hospital and Medical corporations would be able to apply these devices to the existing technology within the hospitals. A caregiver, without access to Wi Fi at home, could have access to and training on a computer/device using text to speech or a screen reader while being with their family member during hospitalization and/or treatment.

### **Conclusion**

Research pertaining to caregiver strain on people with cancer has revealed influential information. The medical professionals working in Oncology, the caregivers, and those receiving the care, are aware of:

1. The strain and anxiety of a caregiver of a person with cancer can be predicted.
2. The strain and anxiety felt by the caregiver will negatively impact the care received by the person with cancer.
3. Informing the caregiver about the possible tasks of caregiving could be improved via the principles of Universal Design and assistive technology. The caregiver should be informed about the tasks of caregiving during the first 5 to 10 days of treatment.

Early knowledge of the tasks involved in caregiving will allow the person to decide what tasks they can do and those that they cannot. Therefore, the predicted strain the caregiver feels may be decreased. The care provided to the person with cancer will not further jeopardize their health/recovery.

Caregivers most commonly become a caregiver by default. Most caregivers are female and over the age of 65. It would not be unusual for a caregiver to have their own health issues such as vision or hearing impairments, memory or concentration difficulties, as well as mobility limitations.

It would be an erroneous assumption to expect a caregiver to possess the skills needed to navigate the Internet. Websites, and other social media, offer valuable information, yet attaining the information can be frustrating.

No matter what assistive technological intervention is provided, caregivers may continue to require one-on-one attention in order to obtain the information needed. It is imperative that medical and health corporations, agencies, and organizations address the needs of all individuals seeking services. Applying the principles of Universal Design to communication and information systems will result in equal access to all individuals.

### ***About the Author***

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## Appendix A

### Informational Survey for Caregivers

By changing the verb tense, the survey could be used as a pre-test, post-test for comparison of increased awareness of the possible tasks involved in caregiving. Terminology and vocabulary level should be changed as needed. Introduce to caregiver within the first 5-10 days of treatment or at least before hospital discharge.

1. I am prepared to be a caregiver to my family member/friend that has cancer.  
Yes\_\_\_\_\_ No, but I know someone I can call for help\_\_\_\_\_ Somewhat\_\_\_\_\_
2. I know who to call for help concerning the medical needs of my family member/friend  
Oncology doctor\_\_\_\_\_ Family doctor\_\_\_\_\_ Oncology nurse\_\_\_\_\_ Hospital social worker\_\_\_\_\_  
Home Health care\_\_\_\_\_ Others\_\_\_\_\_
3. I have an established support system to help me with caregiving tasks.  
Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_
4. I am aware of community resources to help with my family members/friend's needs.  
Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_
5. I am prepared to provide transportation to all doctor appointments  
Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_
6. I am confident in my family member's/friend's financial support.  
Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_
7. I am confident to help my family member's friend's technological medical devices used to communicate with the doctors.  
Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_
8. I am confident to help my family members/friend with their medicine doses.  
Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_
9. I am aware that my family member/friend may lose weight, hair, and clear thinking.  
Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_
10. I am confident in my family member's/friend's insurance company to be helpful.  
Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_
11. I am aware of the possible side effects that chemotherapy treatment will have on my family member/friend.  
Yes \_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

12. I am certain that I will be able to continue my personal plans (work, family vacations)

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

13. I am certain that I will be able to make time for self-care activities (exercise, gardening, reading).

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

14. I am confident to help my family member/friend with their bodily functions.

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

15. I am confident that I will be able to continue to be employed full time.

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

16. I am aware of the possible side effects that radiation treatment will have on my family member/friend.

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

17. I am aware that my family member/friend may need to return to the hospital during treatment.

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

18. I am aware that my family member/friend will experience acute pain and possible chronic pain.

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

19. I am confident that I will be able to complete my daily tasks (grocery, clean house).

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_

20. I am able to discuss the future with my family member/friend who is being treated for cancer.

Yes\_\_\_\_\_ No\_\_\_\_\_ Somewhat\_\_\_\_\_