# Who’s Supporting the Support?; An Analysis of Cancer Family Caregiver Burden and Potential Intervention Strategies

by

**Carolyn Grace Kirby**

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This essay is submitted

by

**Carolyn Grace Kirby**

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and approved by

**Essay Advisor:** Evan Cole, Ph.D. Research Associate Professor, Health Policy and Management, University of Pittsburgh

Essay Reader: Steven Albert, Ph.D., MS, Professor, Behavioral and Community Health Sciences, University of Pittsburgh

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## Abstract

Family caregivers are the silent support system within any care team; their work is underappreciated and goes above and beyond traditional family support. Caregivers provide this care with risks to their own mental, emotional, and physical health. There are many reasons and numerous health concerns that would require family caregivers to step up. One of those is cancer; as a long-term and often debilitating diagnosis, it leads family members to become experts in caring for a loved one as they navigate the complex treatment. As our nation's best researchers and scientists work hard to improve cancer patient outcomes and cures, there needs to be a focus on supporting those helping to carry the weight of cancer's negative consequences and outcomes. This growing public health concern does not require any severe or complex interventions but acknowledges and builds off our health systems existing frameworks. Caring for the caregiver improves health outcomes for patients and caregivers and creates a smoother treatment and care system for all.

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## 1.0 Introduction

As our country continues to grow and develop in healthcare and scientific development, our aging population lives longer and has access to more medical interventions. However, despite our advances in healthcare, some issues remain unaddressed and are in dire need of our focus and attention. Our population continues to age and live longer, and we have to acknowledge the role that informal or family caregivers play in providing the care needed outside of the hospital setting. According to the AARP Caregiving in the U.S report, more than 1 in 5 Americans have been caregivers within the last 12 months (AARP, 2020). That's around 66 million Americans providing care for someone every day, and it is only going to continue growing. Those in the baby boomer generation are living longer, and considering the extreme LTC system burden that the COVID-19 pandemic has created, there's a shortage of workers and a desire of many individuals to stay within their homes (Schulz, Beach, Donovan & Rosland, 2021). The current policy landscape is working hard at the state and federal levels to address this growing issue of providing family caregivers support.

Within the branch of individuals providing informal care to loved ones, the AARP found that 63% of those individuals provided care for someone with a long-term physical condition (AARP, 2020). Within the sector of providing long-term care is individuals providing care to those with cancer. The WHO reports that more than 15 million people will be diagnosed with cancer in 2020 (Wang, Molassiotis, and Chung, 2018). Cancer affects millions of people from all areas, and a common theme connecting these cancer patients is that there is often someone at home caring for them. Providing care for a loved one with cancer can be an extremely taxing and long-term commitment. However, the care these family members offer is crucial in improving the health of cancer patients (Wang et al., 2018). The advanced needs and level of care of cancer patients require means that there must be a focus on caring for the patient and their caregiver to ensure the best possible outcome for all.

## 2.0 Background

This section aims to look at cancer caregivers' specific issues and concerns while understanding and building off general universal caregiver concerns. Being a family caregiver is an intense and challenging role at times, no matter the problem. Caregiving at a national level has become a topic of concern and interest within the U.S political system. In part due to our growing aging population and the COVID-19 pandemic, which brought several health care issues into the spotlight. Understanding the demands of universal caregiving will help break down the unique burden of cancer caregiving and highlight that they are not mutually exclusive but rather a combination of all struggles.

## 2.1 Caregiver Burden

Whether it be for an aging family member, a child, or someone with intellectual and physical disabilities, being a family caregiver is a commitment that requires time, energy, and all available resources. The burden of being a caregiver has been shown to increase health risks mentally and physically (Schulz & Eden, 2016).  The COVID-19 pandemic shifted the narrative around how we care for our loved ones, with social distancing requirements and heightened anxiety making it difficult to manage (Schulz, Beach, Donovan & Rosland, 2021). The University of Pittsburgh did a study and found that when comparing caregivers to non-caregivers during the COVID-19 pandemic, caregivers scored significantly worse than non-caregivers in anxiety, depression, fatigue, and sleep disturbance (Schulz et al., 2021). This research shows that now, more than ever, the burden for caregivers has risen to exceptional heights.

The RAISE Council was created in 2018 under the Secretary of Health and Human Services. Its mission is to understand the pressing issues of family caregivers and address those needs through policy and program changes. A report submitted to Congress in February 2021 highlights some critical points that they found were salient across the caregiver community (RAISE Council, 2021). Some key points can be found below;

- Financial Security
- Respite Care options
- Person/family-centered care adoption
- Information, education, and training
- Care Transitions or coordination

It is evident that, generally, caregivers can pinpoint what they need and how they can be supported. As the RAISE council and advocacy groups work toward making change for all caregivers, it is essential to remember to break down the populations and look at the diverse challenges that different groups under caregiving face. Changing the healthcare framework to better support all caregivers is a widespread, systematic change. But, by focusing on a specific group or population, change and interventions can be designed at the ground level.

## 2.2 Cancer Caregiver

Family caregivers of a cancer patient deal with similar challenges and consequences that other family caregivers will experience when caring for a loved one. However, due to the intense, long-term, and demanding nature of cancer treatment, cancer caregivers have specific challenges and needs that need to be met. Understanding the unique burden of being a cancer caregiver is essential and addressing those needs with creative and custom solutions.

The multilayered issues that family cancer caregivers are dealing with can be broken down into several key areas. A significant component of caregiving for someone with cancer is the higher-level tasks expected to complete. Cancer caregivers are more likely to perform tasks that nursers or professionals would when compared to non-cancer caregivers (Berry, Dalawdi, and Jacboson, 2017). Their responsibilities extend beyond symptom management; it requires frequent and constant monitoring and assessment of the patient (Berry et al., 2017; Kent, Rowland, and Norhouse, 2016). The needed level of care is also constantly shifting as the patient's health progresses or regresses, making it an unpredictable course of care and treatment (Kent et al., 2016). They provide more advanced care, but cancer caregivers also spend more time per day providing care compared to other chronic illnesses (Kent et al., 2016). Due to the high level of care provided, cancer caregivers report feeling unprepared, overwhelmed and stressed about their role (Oeche, Ullrich, Marx, Benze, Heine, Dickel, and Zhang, 2019). With the intense nature of the care cancer givers have to provide, cancer family caregivers report needing better access to mental, emotional, and spiritual support (Kent et al., 2016). Psychological distress is associated with the unmet needs of cancer family caregivers and the caregiver burden (Oeche et al., 2019).

On top of providing extensive care for a loved one, the emotional and mental burden of cancer is a common concern of many cancer caregivers. On average, about 55-90% of family cancer caregivers reported moderate or severe distress during the patient's disease treatment (Oeche et al., 2019). Through surveying families with family members going through palliative care, one study found that the mean level of distress was 7.8 (0-10 scale), 9.4 for anxiety (0-10), and 9.0 for depression (0-10) (Oeche et al., 2019). The emotional burden of caring for and supporting a loved one with cancer is extraordinarily high. Family caregivers are coping with the care they must need to provide while also coping and managing the intense emotions of seeing a loved one undergo treatment and deal with an uncertain future. The emotional strain of this care increases when faced with the end of life treatment (Wang, Molassiostis, Chung & Tan, 2018). A study looking at advanced-stage cancer and family caregivers found that 30% of caregivers reported emotional management as the most challenging part of caregiving (Wang, Molassiostis, Chung & Tan, 2018).

Due to the complex nature of cancer treatment and the treatment planning for cancer. Most studies and research has emphasized patient-provider communication and relationship, which is essential. However, family caregivers are also an important link in the care team and need to be queued into conversations (Washington, Craig, Parker, Ruggeri, Brunk, Goldstein, & Demiris, 2019). The research has been done reported; sparse communication, conflicting or contradictory information, struggle with what questions to ask, and ambivalence from providers about caregiver preferences (Washington et al., 2019). One study done between lung cancer patients and their caregivers assessed how poor or inefficient communication affected The City of Hope Quality of Life Model (Wittenberg, Borneman, Koczywas, Del Ferraro & Ferrell, 2017). The study found that caregivers reported that; communication burdens that occurred from stressful interactions could cause fatigue anxiety (Wittenberg et al., 2017). This study also found that difficulty understanding how to have difficult conversations and share one's emotions around the topic leads to isolation (Wittenberg et al., 2017). For many who have never experienced coping with cancer or other severe illness before, a lack of proper communication can harm their overall health and well-being. If that communication does not exist between the care team and the patient's family, it only increases the caregiver's risk of stress and burden.

Based on the findings from the various studies, the specific issues addressing cancer family caregivers can be categorized as such;

- High-Intensity Level of Care
- Emotional/Mental Burden of Care
- Lack of support and Communication

Using these three categories as the benchmark for specific intervention and change within cancer caregiving will help conceptualize what can be done to ease the burden of cancer caregivers.

## 2.3 Addressing the Issue

When looking at different ways to incorporate and support family caregivers in oncology care, it would be beneficial to build upon the existing frameworks within oncology healthcare. Instead of designing and implementing an entirely new system of support and maintenance, modifying and expanding the existing structures within technology, palliative care, CARE Act, and the role of nurses will provide the most effective results with less effort in redesign and change. Looking at the current literature and comparing it with what cancer caregivers report as the most pressing issue can help design response to this growing issue. Some of these recommendations are based on other Western countries' approaches to integrating family caregivers but can be duplicated within a U.S health care setting.

## 3.0 Existing Frameworks

This section reviews the current literature on methods to support cancer caregivers. Through analyzing what has been studied and attempted,  a better picture can form around what are the viable and possible solutions for cancer caregivers.

### 3.1 Technology

Technology's role in identifying caregivers is crucial for adequate support, education, or training programs. Without access and documentation of family caregivers, there will always be challenges in providing resources to family caregivers. Incorporating a precise tracking system within a healthcare system is the first step beyond assessing the family caregiver and connecting them with the proper tools (Applebaum, Kent, and Lichtenthal, 2015). Using technology to evaluate and connect with family caregivers will benefit all future recommendations for integrating family caregivers into the care team. There are various ways to adopt technology use into assessment for family caregivers. A crucial part of this is identifying who is responsible for monitoring, tracking, and communicating with family caregivers.

After assessment or communication has been developed through technology, those platforms can be used for information sharing, social support, and other multi-component interventions (Shin, Kang, Noll, and Choi, 2018). Information sharing can be done through readings, websites, videos, and in some cases, apps. The main goal of these information-sharing platforms is to educate better patients and their caregivers on their diagnosis and treatment plans.

These programs can improve health literacy around treatment and care, which builds confidence in caregivers (Shin et al., 2018). Using technology as a form for caregivers to address their concerns or questions about the care they are expected to provide within the home will improve the patient health outcomes and caregiver stress.

Social support can be sought through technology to help connect caregivers with peer connections and psychosocial interventions (Shin et al., 2018). Some studies have shown that a clinician-delivered program intended to improve caregivers' efforts can be translated to a web-based platform (Chi and Demiris, 2015). Moving evidence-supported interventions into an online format allows for more accessibility and better time management for caregivers.

Another way that technology has been used to improve the lives of cancer caregivers is through using online assessments and check-ins. This is effective in helping improve the mood of cancer caregivers as it provides more communication between caregiver and physician (Chi and Demiris, 2015). Though many of these implementations are still being worked out and in their trial run phase, it is clear that there are various ways that technology can begin to be utilized.

## 3.2 Palliative Care

Patient-and-family-centered care addresses the needs of family caregivers and their patients to help ease cancer's emotional and psychosocial burden as they go through treatment and the potential for the end-of-life process (May et al., 2021). Those factors of support technically fall under palliative care responsibility. And yet, in many ways, palliative care is still falling short of providing the specific need of cancer patients and cancer caregivers. Particular interventions can be adapted and designed around palliative care to help better support cancer patients and their caregivers.

A study on cancer patients with stage 1 through IV non-small lung cancer and their family caregivers utilized palliative care planning to develop an educational and thorough support program for patients and their family caregiver (Sun, Grant, & Koczywas, 2015). This study found that their palliative care approach to include family caregivers showed significant improvements in social Quality of Life (QOL), psychological distress, and caregiver burden (Sun et al., 2015). This study provides evidence-based support for effective programs to ease the caregiver burden. This program started with assessing who the family caregiver was. Then it went beyond assessment to use that information to help integrate the family caregiver as a crucial member of the care team and understand that their well-being is critical for the cancer patient's long-term care.

An analysis of the current literature on palliative care interventions and family caregivers found that using palliative care to assess caregiver needs, educate about caregiving roles, integrate into the unit of care, and refer caregivers to the appropriate resources, can improve the reported burden of caregiving (Alam, Hannon, and Zimmerman, 2020). The priorities and values of palliative care are centered around improving the quality of life for patients and their families (Alam et al., 2020). Several barriers limit access and use of palliative care; confusion around palliative care, lack of awareness, clinician reluctance, and the reluctance of patients and families (May, Tysinger, Morrison & Jacobson, 2021). The oncology care team, family caregivers, and the palliative care team should have more robust communication to provide complete care for patients and caregivers.

## 3.3 Nurses

Nurses have and always will play a critical role in providing patient care. A study done in 2000 pointed out the increasingly integrated nature of nursing and family caregiver is primarily due to the shift to a focus on home and community-based care (Ward-Griffin and McKeever, 2000). Twenty-two years later and two years into a global pandemic, the demand for at-home and community-based care has grown even more. The text discusses several areas that need to be addressed that can cause barriers to nurses and caregivers working together successfully. Caregivers reported conflicts around; overlapping roles, too rigid roles, caregivers' expertise being dismissed, and when expectations of the medical team and the caregiver contradict (Ward-Griffin and McKeever, 2000). Conflicts between caregivers and nurses can cause negative consequences to the patient and contribute to more stress for all parties involved (Ward-Griffin and McKeever, 2000). With oncology care, the designation of care and roles are ever more intertwined, with a higher demand of maintenance being placed on family caregivers.

When done effectively, the integration and teamwork of family caregivers and nurses improve the lives of the patient and caregiver. Nurses are frequently the health care team members responsible for recording and communicating to the family caregiver the discharge planning for family caregivers (Leighton, Fields, Rodakowski, Feiler, Hawk, Bellon, and James, 2020). Strong family caregiver communication and collaboration with the nursing staff have increased a family caregiver's preparedness to take care of the patient at home (Hagedorn, Keers, Jaarsma, Van Der Schans, Luttik and Paans, 2020). Collaboration between nurses and the family caregivers also makes family caregivers feel more involved in the decision-making process for the patient (Hagedoon et al., 2020). A relationship built from a "partnership" perspective between the nurses and caregivers provided the most positive feedback (Ward-Griffin and McKeever, 2000). When nurses and caregivers work together, patients benefit the most, as communication leads to fewer hospitalizations and a smoother discharge transition for the patient (Haegoon et al., 2020).

### 3.4 CARE Act

The Caregiver, Advise, Record and Enable Act was introduced as a response to an AARP Report that brought attention to the need for effective communication between the healthcare team and the family caregivers (John Hartford Foundation; AARP, 2020). The goal of this Act was to close the gap in these severe communication issues and help family caregivers provide better and more comprehensive care for the patient (AARP, 2020). In its current standing, the CARE Act requires that hospitals record and identify family caregivers of their patients and that discharge plans are discussed between the physicians and the caregiver. The intended product was a smoother and more effective discharge of hospital patients back into their homes and see better health outcomes through family caregiver support (AARP, 2020; Coleman, 2016). The CARE Act was created at the state level due to the complicated nature of passing a law within the federal government. Oklahoma was the first state to pass the bill, and as of June, forty-two states have introduced this bill.

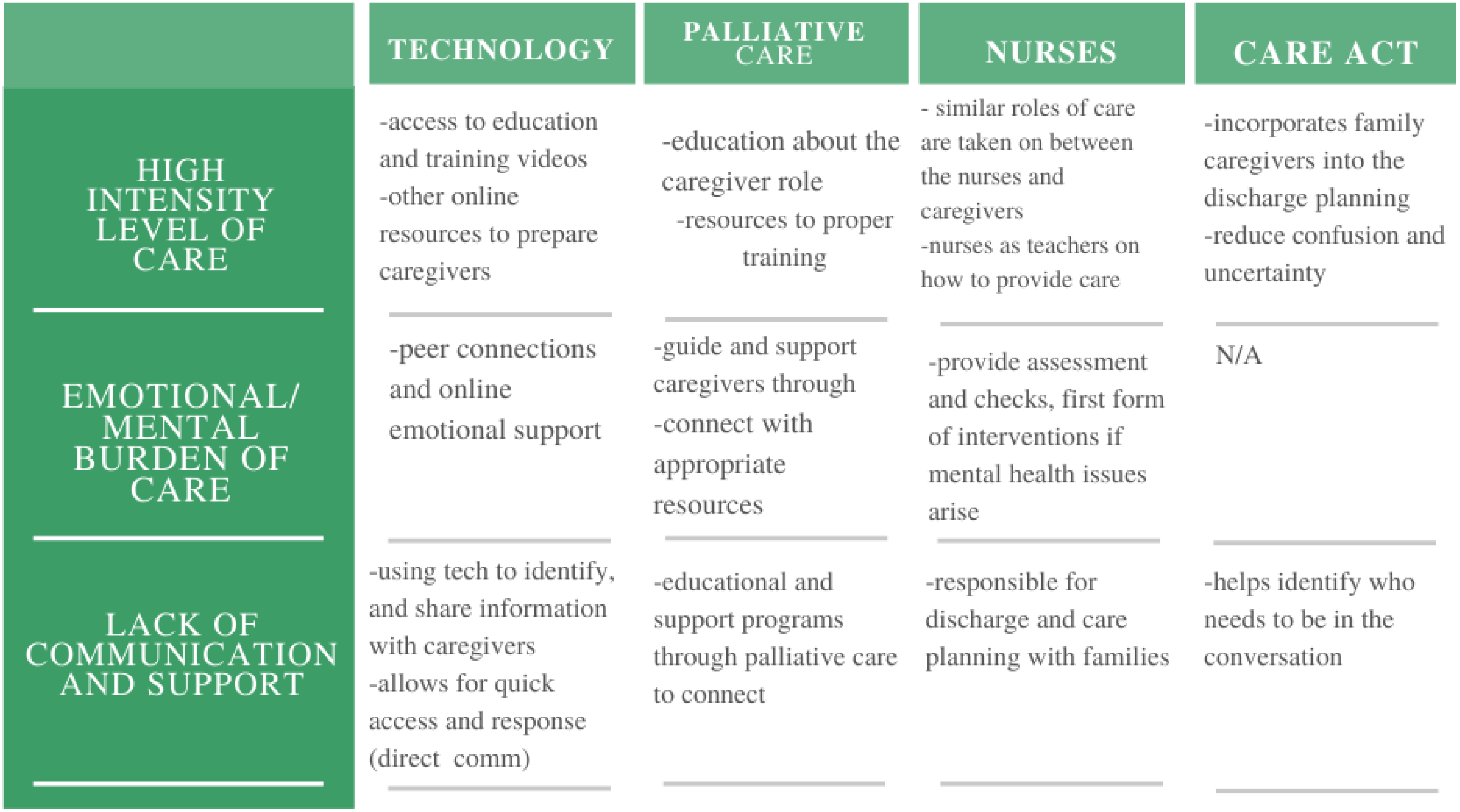
When effectively implemented, the integration of family caregivers into the discharge planning, as the CARE Act intended, has positive outcomes for the individual and the health system field. However, despite the known benefits of this collaboration and communication between patients and the health care team, several barriers hinder the CARE Act from being successfully utilized. A report looking at Pennsylvania hospitals' approaches and views of the CARE Act found that many view complete implementation of the CARE Act as a "process"

(Rodakowski, Leighton, Martsolf, and James, 2020). The first step in the process is identifying the family caregivers and discussing discharge plans, which most hospitals have reported have begun to do so. Aspects of training and education for family caregivers are slower, more time-consuming processes that have yet to be thoroughly developed.

When viewing the CARE Act as a potential pathway to elevate caregiver burden, it is essential to understand that the original intent of the CARE Act was around discharge communication and training of family caregivers for inpatient services. Education and communication are critical to the patient and the family caregiver; it only addresses one aspect of the many family caregivers' needs. When looking at the holistic needs and concerns of cancer caregivers and viewing communication as a bridge for those issues, it would be best to look at existing frameworks and how they can be better utilized to address the needs of cancer caregivers.

## 4.0 Discussion

Cancer caregiving is a complex issue, and a comprehensive approach needs to be considered when approaching potential solutions. **Figure 1.0** connects existing problems with current existing frameworks. By comparing how each may address the various issues, a model can be developed to understand what areas are still lacking and how these programs can be expanded. **Figure 1.0** connects the current pressing issues with the existing frameworks within cancer care.



| | TECHNOLOGY | PALLIATIVE CARE | NURSES | CARE ACT |
|---|---|---|---|---|
| HIGH INTENSITY LEVEL OF CARE | -access to education and training videos<br>-other online resources to prepare caregivers | -education about the caregiver role<br>-resources to proper training | - similar roles of care are taken on between the nurses and caregivers<br>-nurses as teachers on how to provide care | -incorporates family caregivers into the discharge planning<br>-reduce confusion and uncertainty |
| EMOTIONAL/ MENTAL BURDEN OF CARE | -peer connections and online emotional support | -guide and support caregivers through<br>-connect with appropriate resources | -provide assessment and checks, first form of interventions if mental health issues arise | N/A |
| LACK OF COMMUNICATION AND SUPPORT | -using tech to identify, and share information with caregivers<br>-allows for quick access and response (direct comm) | -educational and support programs through palliative care to connect | -responsible for discharge and care planning with families | -helps identify who needs to be in the conversation |

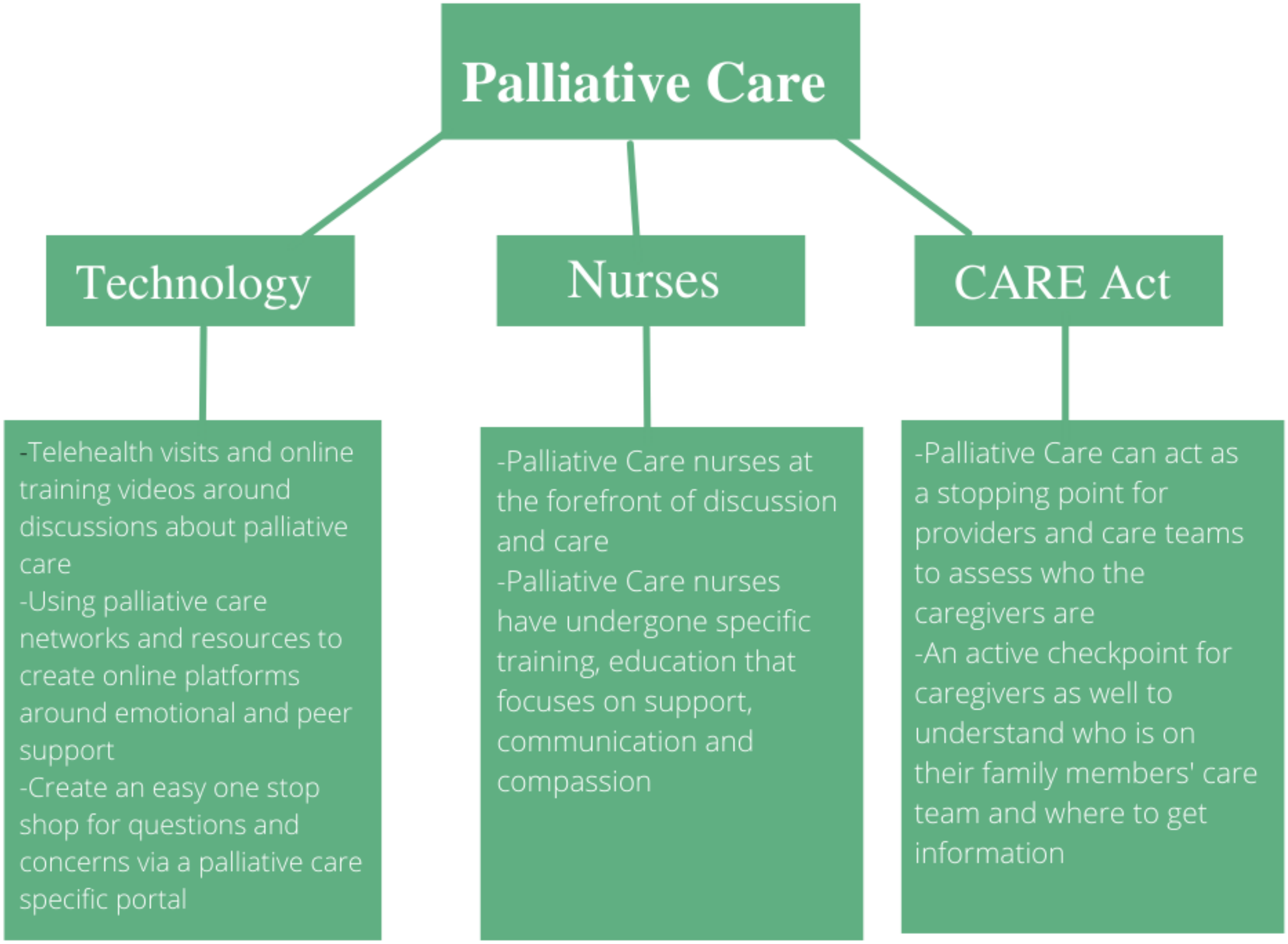
**Figure 1.0**

Through **Figure 1.0**, it is clear that the key issues pulled out of the literature can be addressed through current approaches. And yet, cancer family caregivers are still struggling with a massive gap between what could be offered and offered. Most programs and intervention strategies focus on the patient, and benefits to the caregiver are secondary (May et al., 2021). Knowing what can be done and taking action within the oncology care team requires effort, time, focus, and proper funding. It is also important to note that many issues are not in a vacuum. If a caregiver feels poor communication, that may lead to more emotional distress and, in turn, lead to problems with keeping up with caregiving tasks. Addressing one issue will consequently lead to positive outcomes in another area. Understanding the interdisciplinary nature of these issues and the caregiver's needs is essential when thinking about intervention programs for caregivers. However, that means nothing when the current forms of support are not being used adequately or to their fullest. Cancer is an emotional, physical, and mental rollercoaster that requires the utmost attention. When proper structures exist, the issue lies in implementation, program support, and engagement. A new standard of care must be created that incorporates the appropriate interventions and support for cancer caregivers.

## 5.0 Recommendation

When looking at the most effective intervention method, it is imperative to consider what can best fit all criteria and needs. A holistic solution will provide the best results and outcomes for cancer caregivers. Expanding and improving palliative care in a way that allows it to successfully incorporate not only a patient-physician relationship but a physician-caregiver-patient relationship. Palliative care can successfully rely on technology tools to address current issues and also requires skilled and tactful nurses to run smoothly and effectively (Schroeder & Lorenz, 2018; Worster & Swartz, 2017). A massive disservice is done when Palliative Care is only viewed as hospice or end-of-life care (May et al., 2021). There is an opportunity to use the existing frameworks within Palliative Care and incorporate other effective methods such as technology and nurses to close the gap in cancer caregiver care.

A new model can show how Palliative Care can act as the primary point that other services stem from. **Figure 2.0** represents what that could look like with focusing on all effective intervention programs under Palliative Care.



**Palliative Care**

**Technology**

-Telehealth visits and online training videos around discussions about palliative care

-Using palliative care networks and resources to create online platforms around emotional and peer support

-Create an easy one stop shop for questions and concerns via a palliative care specific portal

**Nurses**

-Palliative Care nurses at the forefront of discussion and care

-Palliative Care nurses have undergone specific training, education that focuses on support, communication and compassion

**CARE Act**

-Palliative Care can act as a stopping point for providers and care teams to assess who the caregivers are

-An active checkpoint for caregivers as well to understand who is on their family members' care team and where to get information

**Figure 2.0**

## 6.0 Conclusion

Nobody wants to go through the diagnosis and treatment of cancer alone, and no one wants to watch a loved one suffer. And yet, the CDC reports that more than 1.6 million people each year will be diagnosed with some form of cancer, with nearly 600,000 people dying from it each year (CDC, 2020). This is an issue that cannot be avoided or ignored, and when viewing the issue, the best approach considers all factors that play into the outcomes. Cancer family caregivers will experience more stress, anxiety, exhaustion, and depression than non-caregivers, while also providing advanced levels of care.

Palliative Care offers an opportunity for growth and involvement for several interventions to be successfully implemented to support cancer caregivers. Palliative care can adopt a more robust model of technology that allows for online support, conversations, quick telehealth visits, and educational/training visits. Telehealth allows busy nurses and physicians to ensure specific online space for caregivers to refer. Due to their particular training and education, Palliative care nurses are vital in ensuring that family caregivers feel seen and heard. The CARE Act acts as a benchmark and pillar for communication and recognizing family caregivers' role in the patient's care.

The Palliative Care system is interconnected, with no role being isolated in one category or the next. It is important to remember that when understanding interventions for family caregivers, as it is a multidimensional issue with overlap everywhere. Instead of addressing the problem one intervention at a time, it would be more efficient to focus on how all can work together to build a more sustainable model of support and care for cancer family caregivers.

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