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Addressing Caregiver Burden Among Oncology Caregivers: An Educational Intervention

by

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Abstract

The incidence of cancer is on the rise, the number of cancer diagnoses are increasing at an alarming rate with advanced technologies and available evidence. Cancer care has also shifted from the inpatient setting to mostly outpatient. With this, a large portion of the responsibility has been transferred to the caregiver of that patient (Kent et al., 2019). Historically, caregivers have not been at the forefront of research, however, the concept of caregiver burden is beginning to emerge. A gap exists in addressing the needs of caregivers in both evidence-based data and with the local community cancer support group, Gilda's Club. The purpose of this Doctor of Nursing Practice (DNP) project was to enrich the cancer caregiver experience by collaborating with Gilda's Club to implement a six-week intervention, focused on the cancer caregiver, and therefore decreasing their perceived burden. The program consisted of weekly modules addressing common concerns and educational gaps in cancer care, particularly those pertaining to the cancer caregiver. The evaluation method utilized was the Zarit Caregiver Burden Assessment (12-item) and percent change using Microsoft Excel. The overall aim of this DNP project was to decrease caregiver burden.

Keywords: cancer, caregivers, burden, Zarit Caregiver Burden Assessment

Table of Contents

Addressing Caregiver Burden Among Oncology Caregivers: An Educational Intervention

Current cancer therapies have changed the landscape of patient care allowing patients to have both longer lives while receiving the majority of their care as an outpatient. While this can positively augment the cancer care experience for patients, this has inadvertently increased the responsibility and burden experienced by the caregivers of those patients. Data describes that "cancer caregiving is intense, episodic, and has a profound impact on the caregiver's well-being and quality of life" (Sun et al., 2019, p.2). In addition, caregivers play an integral role in the care of the cancer patient together with the provider.

Gilda's Club is a local organization located in Louisville, Kentucky that is dedicated to supporting those affected by cancer and their caregivers. Gilda's Club has various health and wellness, fellowship, and support programs for those actively going through cancer treatments and for those after cancer treatment has completed. Gilda's Club states that, "At Gilda's Club Kentuckiana our mission is to ensure those impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. We are dedicated to creating a support system unlike any other" (Gilda's Club Kentuckiana, 2023). Gilda's Clubs' purpose seeks to connect patients, family members, friends, loved ones, and caregivers with professionally managed programs that seek to improve quality of life of those impacted by cancer. From the moment a person receives a cancer diagnosis they can find solace and support. Gilda's Club is named in memory of the Saturday Night Live star Gilda Radner. Gilda was diagnosed with ovarian cancer and together with her psychotherapist, they believed that were was a correlation between emotional and physical well-being. The first Gilda's Club was located in New York City. Gilda's Club has many resources for cancer patients including reiki, social dinners, music therapy, tai chi, yoga, art, and knitting. However, there are no formal programs that are specifically tailored for the cancer caregiver. The purpose of this DNP project was to enrich the cancer caregiver's experience by collaborating with Gilda's Club to implement a six-week educational intervention focused on the cancer caregiver, and therefore, decreasing their perceived burden.

Background and Significance of the Problem

The prevalence of cancer in the United States is increasing. "In 2023 a total of 1,958,310 new cancer cases and 609,820 cancer deaths are projected to occur" (Siegal et al., 2023). As individuals that are affected by cancer increase, the number of those who care for them increases proportionately. Kent et al. (2019) describes that, "these numbers are expected to increase over time given the aging population and improvements in survival. Many cancer patients and survivors require care for months or years, even after the end of active treatment because of late and long-term effects of cancer and therapy. The growth in the prevalence of cancer and shift towards outpatient care has placed an increased burden on informal caregivers".

External evidence illuminates to three potential contributing factors to caregiver stress; lack of medical literacy, financial burden, and poor quality of life. Many caregivers are informal; not trained medical professionals. They often consist of family members, neighbors, and friends. There are certain gaps in knowledge for a person without medical training or knowledge when it comes to cancer caregiving. Care of the cancer patient can include treatment of intricate symptoms, administering complicated medication regimens, and recognizing emergent signs of a decline. Contributing to this gap with certain individuals could be a lack of literacy due to a lower socioeconomic status or opportunity (Gutovenko et al.,2021).

The cost of cancer treatment is skyrocketing and can be a financial burden, "financial toxicity affects patients across all types and spectrums of cancer care" (Abrams, 2021, p.2044).

The American Society of Clinical Oncology "recognized cancer costs as burdensome to patients" (Abrams, 2021, p. 2044). Recognizing the financial burden on patients and their caregivers is essential to consider as a factor contributing to increased caregiver stress. The financial aspects of cancer care begin at the time of diagnosis and can continue for the lifespan of the cancer patient; even beyond the time a patient is deemed cancer free. The most impactful factor identified was the change in quality of life of the caregiver; consequently "poor psychosocial health of the caregiver leads to poorer outcomes for the patient (Reema et al., 2021, p.2).

Quality of life includes both physical and mental aspects. The American Cancer Society, Center for Disease Control (CDC), and National Institute of Cancer have dedicated resources acknowledging the change that caregiving presents and ways for the caregiver to prioritize their own health. The American Psychological Association (APA) recognizes that women and older adults are more apt to distress with caregiving. Older adults are at increased risk for minor injuries becoming more serious and women are often found to be managing several different roles (APA, 2015).

The primary patient or member of Gilda's Club includes both the patient experiencing cancer treatments and their entire support system. This includes but is not limited to friends, family, and caregivers. Gilda's Club hosts programs for men, women, and children and serves all types of cancers. The number of patients fluctuates at any given time due to the nature of the disease and the type of cancer. Patients come to Gilda's Club from the various health systems in Louisville, KY. Joining Gilda's Club is voluntary, and all members get from the club whatever they are willing to contribute. They are required to register themselves for the programs offered. There are staff members that assist those interested and navigate the resources offered. Upon evaluation of the Gilda's Club monthly schedule, it was noted that most programs are tailored for the cancer patient, with one or two support groups including the caregiver or other support system for the patient. Gilda's Club is a great example of interprofessional collaboration to serve those affected by cancer in the community by having a multidisciplinary approach with social workers, translators, and provider speakers for their programs. However, there are no designated programs available that address the external factors that contribute to caregiver burden; lack of medical literacy, financial burden, and poor quality of life. Patterns that are present in this local Gilda's Club microsystem include a succinct way of signing up new members and this is a large source of strength contributing to the need for two centers. Through all of this, the focus of their programs is on the cancer patient. There is a true need to offer more targeted resources directed at the cancer caregiver.

Literature Review

Historically, research has not been geared towards supporting the caregiver; however, a recent shift in priority is apparent. Swartz and Collins (2019) confirm that "supporting this invisible and isolated army" has become preferential (p.699). It is crucial that factors increasing caregiver burden be identified and research completed to address these burdens. When caregivers are given aid, patient outcomes can be given a chance to excel. Elements of the caregiver experience that could contribute to increased burden or stress include but are not limited to lack of medical literacy, financial burden, poor quality of life determined by physical or mental contributors, lack of resources or time to properly address the care needed for the patient, and finally outside responsibilities. This review of the literature examines and synthesizes current evidence regarding related to the improvement of caregiver burden.

Literature Search Methods

Various search engines were utilized to compile articles related to the project of caregiver burden. Articles were reviewed in PUBMED, CINAL, Medline, Embase, PsychInfo, and Cochrane library. The key words used in the search included: "caregiver", "caregiver stress", "neoplasms", "oncology or cancer", "quality of life", and "mental stress". These terms were connected by Boolean strings, when necessary, specifically in PubMed.

PubMed was used as the primary search engine which resulted in 20,053 articles. Publications were limited to those within the last five years and those written in the English language for all searches. Intervention articles included were those that were a meta- analysis, randomized control trials (RCT), systemic review, or clinical trials. This yielded 1,040 publications. Twenty-two articles were eliminated due to duplication. CINAHL was utilized next, which yielded 74 articles. Ten were identified as relevant to the topic. After searching Medline, 50 articles resulted and 18 articles were deemed appropriate. Embase was searched next and yielded 238 articles, 60 of those were identified as suitable. PsychINFO yielded 364 articles and 35 were identified as relevant to the topic. Lastly, Cochrane library was searched and yielded 483 results and 102 articles were relevant to the topic. Abstracts of each article remaining were reviewed for relevance to the topic and quality and strength of study with the LEGEND model by Cincinnati Children's. This ultimately led to 20 articles that were deemed applicable for this integrative review. There were two articles which were identified using a hand search method using the terms "caregiver burden" and "interventions". Thus, a total of 22 articles were examined.

The articles selected for this review sought to improve upon several elements contributing to caregiver burden of cancer patients. The variables included in this literature review include psychological distress, quality of life, stress levels, self-efficacy, confidence for caregiving, anxiety, depression, social support, spiritual well-being, physical well-being, caregiver burden, coping measures, and communication with patient. There were multiple different methods of delivery of interventions used including face- to face meetings, telephone, internet- based, a combination of telephone and face to face, or a combination of internet based and face to face.

Face -to Face Meetings

Eleven articles utilized face to face meetings as the delivery method for their caregiver interventions. Ozcan et al. (2021) described a mixed method, qualitative and RCT in an oncological unit in Turkey. A total of 42 caregivers were split into two groups to evaluate the effect of Reiki on stress levels of caregivers. The study supported that Reiki did reduce the stress levels of caregivers in the study ($p < .05$). This was of excellent quality study but a small sample. Although it is suggested that Reiki would decrease stress levels, more data is needed. A replicated study with a larger sample could reinforce the findings. Toygar et al. (2020) described an RCT of 66 informal caregivers looking at foot reflexology effect on sleep and anxiety. It was found that reflexology has a large effect on anxiety($p<.001$) and a medium effect on sleep($p=.001$). Again, similar to the findings described above, a replication with a larger sample would further support the results. Xiu et al. (2020) presented an RCT of 157 Chinese informal caregivers of lung cancer patients. It sought to assess the effect of culturally compatible psychosocial interventions on depression, anxiety, stress, insomnia, quality of life, and caregiver burden. The interventions selected for the study included two groups; a mind-body-spirit intervention or cognitive behavioral therapy. Both groups demonstrated a statistically significant improvement in all variables, despite that p values were not provided. This study suggested that caregiver depression could be linked to unresolved burden from caregiving that is “multidimensional”. Caregiver burdens are likely related to external circumstances such as lack of family support and schedules. Wang et al. (2021) described an RCT that included 68 patient-caregiver dyads at the Fujian Medical University. This study examined the effects of a family dignity program on the variables of patient hope, caregivers’ depression and anxiety, and family cohesion. This resulted in a significantly lowered level of anxiety($p=.037$) and depression($p=.001$) among caregivers. Family adaptivity was increased as well($p=.036$). Even though this illustrated promise in the family participatory dignity therapy program, it was a single site study. A longer length of time to follow up would increase the strength of this study. Laudenslager et al. (2019) described an RCT in two regional sites in Denver, Colorado with samples of 98 and 61 respectively. This study sought to compare treatment as usual and a psychoeducation paced respiration and relaxation program (PEPRR) in the variables of quality of life, caregiver distress, depression, anxiety, perceived stress, and caregiver burden. At the 6-month interval no significant difference was identified; with the exception of caregiver distress. Lee et al. (2021) described a global systematic review of 14 RCT's among 2,380 caregivers. This evaluated the interventions of patient care needs, caregiver self-care needs, enhancing relationships, and mobilizing additional community of family support and their effect on quality of life, depression, and anxiety. All psychosocial interventions were efficacious in improving quality of life and depression. A portion of the RCT's reviewed did have bias and did have a smaller sample size. No p values were listed for this study. Mahendran et al. (2017) described a quasi-experimental mixed methods study evaluating the psychosocial educational support group (COPE) intervention on depression, anxiety, and quality of life. The sample included 97 participants located in Asia. This study utilized both quantitative and qualitative methods for evaluation. The quantitative evaluation demonstrated that the intervention group of the study did have a significant improvement in quality of life ($p=.053$), however depression and anxiety did not demonstrate significant differences. The qualitative evaluation suggests that this improvement was due to providing coping skills to the caregiver sample. Some participants were lost to follow up due to scheduling conflicts with the sessions. Additional research regarding the COPE method could prove to be fruitful. Marsland et al. (2020) described an RCT of 120 mothers of children newly diagnosed with cancer in Pittsburgh, Pennsylvania. The Connections to Coping (CTC) method was utilized to determine effects on psychological function and physical health of the mothers. Results from this study supported that the intervention reduced perceived stress and anxiety. However, this study focused on mothers with external variables to consider that may have contributed to perceived stress and anxiety. Physical health did not have an impact after the intervention performed. *P* values were not provided in this data, only that variables were significant. Liu et al. (2020) described an RCT with a longitudinal repeated measure design that considered 60 caregivers from a pediatric hospital in Taiwan. A nurse facilitated family support intervention was implemented in regard to anxiety, depression, caregiver stress, and quality of life. Caregivers did reveal lower levels of depression, perceived stress, and an increased level of quality of life (*p=.01).* This study again supports that giving additional support helps to improve variables that contribute to caregiver burden. Petursdottir et al. (2021) described a longitudinal study of 24 caregivers comparing a therapeutic conversation intervention and a control group on depression, anxiety, and stress levels following a loss. Results from this study support a significant decreas in anxiety *(p=.047)* and stress *(p=.0048)*. This study acknowledged that the intervention could have been introduced earlier in the loss process for maximum impact. Again, the sample size is quite small so the ability to replicate would need to be considered for generalization. Senneseth et al. (2017) described an RCT of 35 spouses of cancer patients to determine if the Cancer-PEPSONE Program (CPP) improved upon perceived/ received social support, psychological distress, and quality of life. Results demonstrated that CPP was not impactful with psychological distress of spouses. A note of importance, only 24 participants were included in the three month follow up. The data from the studies highly supported that face- to -face methods are effective in improving cancer caregiver burden.

Telephone meetings

One article utilized telephone meetings as a delivery method for their interventions. Badger et al. described an RCT design with longitudinal assessments, in the Latina population of Arizona, in which 230 survivor-caregiver dyads were studied for depression, anxiety, stress, and social support (2020). The study utilized either telephone interpersonal counseling (TIPC) or Supportive Health Education (SHE). SHE was found to be the more impactful method in anxiety and cancer related symptom management, while TIPC showed superior benefits for depression management *(p=.04)*. Since this was only studied in the Latina population, concerns with replication should be acknowledged. This study revealed promise for an educational approach in increasing overall quality of life.

Internet-based Methods

Kubo et al. (2019) and Li et al. (2022) both utilized internet-based methods as a delivery method for their interventions. Kubo et al. described a RCT design in which 72 cancer patients and their 26 caregivers from a Northern California center were studied for distress, anxiety, depression, pain, sleep quality, quality of life, fatigue, and mindfulness (2019). The study utilized an internet-based mindfulness/educational intervention that could also be accessed on mobile phones. Patient scores improved in all variables, however caregiver scores only improved in mindfulness *(p=.03)*. Given most improvements were seen in the patient population, this study can be used to evaluate the impact of accessibility. Li et al. described a systematic review and meta-analysis of seven RCT’s analyzing the impact of an e-health or internet-based intervention on caregiver burden, depression, anxiety, and overall quality of life. This meta-analysis endorsed that the internet-based interventions significantly improved depression and quality of life; but not caregiver burden. Sensitivity analysis showed that caregiver burden was stable (2022). Although the data regarding internet-based interventions was not robust, these studies upheld the idea that this delivery method is promising.

Combination of telephone and face to face meetings

Six articles utilized a combination of telephone and face to face meetings as a delivery method for their intervention. Al Daken et al. (2018) described a systematic review of 11 distinct levels of studies determining effectiveness of mindfulness-based interventions (MBI) and educational interventions (EI) in patients with cancer receiving palliative care and caregivers of patients with cancer. The review addressed psychological, emotional, functional, spiritual well-being, mindfulness, physical symptoms, and cortisol level variables. Preliminary findings supported the effectiveness of MBI and EI for caregivers. MBI exhibit positive results in enhancing physical, mental, and emotional well-being. EI's were shown to have a positive impact as well. No *p* values were listed. Wagle et al. (2018) described a systematic review of RCT's and quasi -experimental trials. The authors evaluated caregiver satisfaction measured by quality of life, emotional well-being, and caregiver burden. Of these studies, only caregiver satisfaction was improved. The quasi-experimental trials evaluated re-hospitalization rates, medication appropriateness, medication knowledge, and caregiver preparedness. Of these studies caregiver satisfaction and caregiver confidence increased. All of these studies were small and mostly single site; therefore, replicability is a concern. No *p* values were listed. Cheng et al. (2022) presented a systematic review and meta-analysis of RCT's performed globally with a total of 1818 caregivers. These studies addressed variables such as anxiety, depression, distress, quality of life, caregiver competence, and caregiver burden. Interventions were telephone-based education, written materials, audiotapes, videos, discussion, presentations, home assignments, and in-person meetings. All psychoeducation interventions did have a short-term positive effect on all variables, data is lacking for long term effects. Although some studies did not evaluate mean or standard deviation, it supported that psychoeducation interventions are promising for improving the caregiver experience. Mosher et al. (2018) described an RCT of 50 advanced gastrointestinal cancer patients and caregiver dyads in the Veteran's Medical Center of Indianapolis and Indiana University. The variables evaluated were the meaning of life, physical symptoms such as fatigue, and psychological symptoms including depression and anxiety. This study was particularly interesting because it built on the understanding that the telephone-based method enhanced caregiver experience by adding an in person, peer addition to meet with dyads. It demonstrated that the peer addition did not add to the improvement compared to the telephone alone interventions. The only significant change was in the meaning of life *(p=.01).* Trevino et al. (2021) described an RCT that examined 29 patient and caregiver dyads using the intervention of cognitive behavioral therapy (CBT) as a tool to manage anxiety from cancer. This study assessed variables of anxiety, depression, and quality of life using this intervention. It unveiled that there was no statistical significance, although improvements were seen in caregivers in anxiety, all *p* values were greater than .01. This study was performed with a small sample, trials with larger samples are warranted. Ahn et al. (2020) described a systematic review of nine RCT's and two quasi -experimental studies. There were 2,369 participants were included in this global systematic review. Interventions of telephone support, a protocol with signs of stress and burnout and management of emotions, educational/ informational interventions, and an intervention focused on family involvement were explored Variables such as psychological distress, quality of life, caregiver burden, self-efficacy, and competence for caregiving were evaluated. This review endorsed that caregivers have a need for unmet information, psychological, and support needs. Support interventions used in this study identified great potential for enhancing caregiver psychological symptoms, quality of life, caregiving burden, self-efficacy, and competence for caregiving. No significant *p* values were listed. The combinations of telephone and face to face meetings reviewed did not show that the interventions used were statistically significant, therefore one would be unable to comment if these were useful.

Combination of internet-based methods and face to face meetings

Two articles utilized a combination of internet-based methods and face to face meetings as a delivery method for their interventions. Frambes et al. (2018) described a systematic review of 14 RCT's that evaluated relationships between supportive interventions for caregivers, the care activities performed, caregiver characteristics, and resulting caregiver outcomes. This systemic review was impactful as it included 14 RCT's and supported the idea that improvements were noted when offering methods both in an internet-based matter and in person. Kedia et al. (2020) described a systematic review of seven RCT's, five pre and post intervention trial, four quasi - experimental trials, one randomized pilot trials, and one qualitative study. This review measured burden, mental health, quality of life, self-efficacy, and coping/outcome measures. Improvements were seen in all variables. The data from these two reviews highly supported the need for multifaceted delivery methods as the both exhibited improved outcomes.

Discussion of Current Literature

The majority of articles included for this review were either RCT's or systematic reviews. Of the articles, 14 were of lesser quality and eight were good quality based on the LEGEND model by Cincinnati Children's. Although the majority of articles were lesser quality based on this model, they were scored less based on small sample size and concern for replicability. The overwhelming theme identified in this review was that some form of psychosocial intervention was utilized; whether it be educational in nature or supportive. All aimed to improve variables in the quality of life of caregivers. The common main barrier that was identified was related to the delivery of the intervention. If the intervention was delivered in person, excluded those who did not have transportation or room in their schedules to receive the intervention. A similar concept holds true for studies that did only telephone or only internet-based delivery modalities. By offering the intervention in a variety of ways it allowed for greater inclusivity. A discussion regarding barriers would be incomplete if it did not address social economic status. A portion of the studies were in small minority groups who likely had a decreased level of resources and disparity of care than other samples. This would impact the outcomes of the study. Considering the knowledge gained from the review of literature, this DNP project focused on a psychosocial intervention and was delivered to participants in multiple modalities. This would allow for greater inclusivity among the participants.

With the advent of new therapies directed at treating cancer, shifting caregiving from hospitals and other traditional locations to outpatient areas and the home, there is also a shift in the amount of burden placed on the responsible party of that patient. This creates a need for improvements in caregiver burden. Research historically has not been conducted to address these issues; however, it is emerging with new ideas. The literature appraisal has identified methods that significantly contributed to this change. Although eliminating burden completely is not a possibility, there is a need to augment the caregiver experience. Not only would this enrich the caregiver's experience, but it could also contribute to better outcomes for the cancer patient.

Problem to Solve and Rationale

It is paramount that additional support be provided to caregivers for the best interest of the cancer patient as it can contribute to better patient outcomes. Kent et al. (2019) states that "research conducted on caregivers is limited because of limited data and challenges with identifying and surveying caregivers. Surveys have not used consistent approaches to capture caregiver burden, and there is substantial variation in the types of survey questions about caregiving experience". Gilda's Club is a local group located in Louisville, Kentucky that is dedicated to supporting those affected by cancer. They have various health and wellness, fellowship, and support programs for those actively going through cancer treatments and for those after treatment has been completed. A needs assessment was conducted with the Program and Impact officer at Gilda’s Club. This discussion identified a need for an expanded cancer caregiver support program. The programs that are offered at Gilda’s Club are tailored towards survivors and not necessarily their support system. This review of the literature consistently demonstrates there is a level of stress related to the caregivers of cancer patients and additional support for caregivers is warranted. All data evaluated unanimously supports an intervention to assist with cancer caregiver burden.

Caregiver Stress: External Evidence

External evidence denotes three potential contributing factors to caregiver stress; lack of medical literacy, financial burden, and poor quality of life. Most caregivers are not medically trained professionals. They primarily consist of family members, neighbors, and friends. There are certain gaps in knowledge for a person not in the medical field when it comes to cancer caregiving with its intricate symptoms, medications, and ability to recognize an emergent situation or signs of patient decline. Contributing to this gap with certain individuals could be a lack of literacy due to a lower socioeconomic status or opportunity (Gutovenko et al.,2021).

The American Society of Clinical Oncology “recognized cancer costs as burdensome to patients” (Abrams et al., 2021, p.2044). The financial burden on patients and their caregivers must be addressed as a factor that could lead to increased caregiver stress. The financial aspects of cancer care begin at the start of diagnosis and continue for the patient’s lifespan. Most patients do not have funds set aside for a disease that they are not expecting. There are several drivers to the amount of financial burden including but not limited to insurance coverage, cost of medications, maintaining insurance depending on work status, length or types of therapy, and lack of income. Finances impact all patients and caregivers differently. The most impactful factor identified was the change in quality of life of the caregiver; "poor psychosocial health of the caregiver leads to poorer outcomes for the patient (Reema et al., 2021, p.2). Quality of life includes both physical and mental aspects. The American Cancer Society, CDC, and National Institute of Cancer have dedicated resources acknowledging the change that caregiving presents and ways for the caregiver to first take care of themselves. The American Cancer Society acknowledges the importance of setting limits if this role was not wanted or given based on others not wanting to help (2022). Mental stress, anxiety and depression are quite common in caregivers. It is important to acknowledge feelings of anxiousness, loneliness, guilt, and worry about the future (National Cancer Institute, 2019). Of course, all of these resources will not change the worry about the potential loss of a loved one and their cancer course. The caregiver should find ways to stay physically healthy as well, limiting or eliminating smoking or alcohol consumption, keeping medical appointments, and eating a balanced diet (CDC, 2022). The APA mentions that women and older adults are more apt to distress with caregiving. Older adults are more at risk for smaller injuries becoming more serious and women are often pulled in many directions (APA, 2015). All caregivers might enter into this new cancer diagnosis with their own comorbidities that are important to not exacerbate.

Caregiver Stress: Internal Evidence

Gilda's Club has two locations in the city that were of interest for this DNP; one in St. Matthews (east side of town) and Gilda's West, located in the west end of the city. A needs assessment was performed at Gilda's Club in Louisville, KY, St. Matthews. Gilda's Club has many resources for those living with cancer, few resources are designated for cancer caregivers. There is a designated lounge area at Gilda's Club for caregivers to visit and find resources online (Gilda's Club Kentuckiana, 2023). The programs offered at Gilda's Club are focused on navigating the cancer process; before, during, and after, and the overall health of the cancer patient, programs are limited for the cancer caregiver.

The main factor contributing to additional caregiver burden is the gift of time. Cancer treatments require a massive amount of time commitment, including the actual treatments such as chemotherapy or radiation, various scans, and follow- ups with the treating providers. Depending on the length of treatment, time commitment from the caregiver can vary. Caregivers might need to take short or long-term disability to help fulfill this responsibility. Given this additional responsibility, caregivers might not have time to attend support groups or explore other resources that could be beneficial.

Another factor contributing to caregiver burden identified, is caring for the elderly patient or a patient with cancer related fatigue. These patients might require more physical assistance from the caregiver given their age or treatment related fatigue from chemotherapy or radiation (Werdani, 2018). Caregivers might not have optimal health themselves and might not be able to safely meet the physical demands of proper care. The older adult patient might require additional attention due to dementia or various co-morbidities prior to the cancer diagnosis (Van Ryn et al., 2011). Older patients may also experience polypharmacy. Additional attention to detail is required to verify that these medications are given at the proper time with proper dosing. Cancer patients generally are prescribed additional medications that can add to this burden as well. An older patient also has an additional risk of increased acuity, this may or may not include metastatic disease, leading to hospitalization (U.S. Department of Health and Human Sciences, 2021).

Many caregivers have other responsibilities besides caring for the cancer individual (Van Ryn et al., 2011). Many caregivers often have family responsibilities; this includes cooking, housekeeping, transporting children, and life coordination. Assuming the role of the cancer caregiver can cause exponential stress. Johansen et al. (2018) specifically addresses that if a female is either the caregiver or patient it can increase stress in the form of sleep disturbances.

Caregivers without access to viable resources have increased stress (Van Ryn et al., 2011). Lack of resources and low socioeconomic status both increase burdens and serve as a barrier for the cancer caregiver to care for themselves. Specifically, transportation, access to care, and employment responsibilities contribute to cancer caregiver's burden.

Decision making or the inability of the cancer patient to make decisions places an additional burden on the cancer caregiver. The cancer caregiver may have to assume the role of power of attorney status or healthcare surrogate. The process for completing this paperwork and legal consultation can be time-consuming and costly.

Interventions that include palliative care sooner rather than later have the best outcomes for patients (Greer et al., 2020). End of life care and decisions contribute to an increase in burden on caregivers. Will the patient decline enough that they require more assistance; including long-term care or hospice? If hospice is required, when is it initiated? Should alternative treatment options be considered?

Purpose and Specific Aims

The purpose of this DNP project was to enrich the cancer caregiver experience by collaborating with Gilda’s Club to implement a six-week educational intervention, focused on the cancer caregiver, decreasing their perceived burden.

Specific aims of the DNP project were to decrease perceived burden of the cancer caregiver as indicated by the Zarit Caregiver Burden Assessment tool (Zarit et al., 1980). Additional aims include a direct impact on the cancer patient caregiver and to develop a sustainable support program for cancer caregivers at Gilda’s Club. The direct impact on the cancer patient includes better health outcomes as it has been demonstrated that as the perceived burden of cancer care giving is decreased on the caregiver, cancer patient outcomes are improved (Litzelman, 2019). A portion of this intervention will also focus on palliative care and hospice with the goal to increase utilization of hospice and palliative care among cancer patients and demonstrate an increase in length of stay in the Hospice programs. Increasing palliative services utilization has the potential to decrease inpatient admission costs secondary to cancer care complications.

The project was made available for use beyond the initial administration as a resource for incoming caregivers at Gilda’s Club proving sustainability. This was accomplished by placing it on Gilda’s Club website.

Conceptual Model

The conceptual framework utilized for this DNP project is Barker’s Tidal Model of Mental Health Recovery, which emerged in the 1990’s. This model “emphasizes helping people reclaim their voice” and states that “a person’s individual mental well-being is dependent on perceptions” (*Barker's Tidal Model of Mental Health Recovery*, 2019). There are six assumptions in Barker’s Tidal Model: (1) a belief in the virtue of curiosity, (2) recognizing resourcefulness, (3) respect for patient’s wishes, (4) accepts that a crisis is an opportunity, (5) all goals must belong to patient, and finally (6) the simplest means should be sought out (*Barker's Tidal Model of Mental Health Recovery*, 2019). This DNP project aims to decrease burden among caregivers by providing them with information and empowering them with knowledge that they might not have held in order to allow for a “recovery” in stress levels. The model specifically described patients, however the DNP Lead extrapolated this to the cancer caregiver.

This DNP intervention addressed educational items related to the overall cancer care that caregivers will use. The overall goal was to impact mental health and therefore allow caregivers to reclaim their voice in caregiving and feel empowered with knowledge regarding patient care.

Methods

The DNP project included a six-week educational intervention aimed at decreasing the burden for cancer caregivers. The weekly module titles were as follows: a.) common cancer terminology and tests, b.) common medications for symptom management, c.) caregiver care, d.) power of attorney information, and e.) hospice and/or palliative concerns. The program focused on various potential aspects of burden in the cancer caregiver with application of the conceptual model of Barker's Tidal Model of Mental Health Recovery (*Barker's Tidal Model of Mental Health Recovery*, 2019). Cancer caregiver burden was measured pre and post intervention utilizing the Zarit Caregiver Burden Assessment (ZCBA), the 12-item questionnaire. ZCBA is a validated tool and does not require permission for use in academic settings. Each of the twelve questions is evaluated on a five-point Likert scale from 0 (never) to 4 (nearly always) (APA, 2011). Week one included introductions, project consent, and the administration and comprehension of the Zarit Caregiver Burden Assessment tool. This reflected on the first assumption Barker's Tidal Model of Mental Health Recovery: a belief in curiosity. This is supported by the philosophy that if a cancer caregiver is willing to participate in this DNP project, a true curiosity exist and that the ability to be a cancer caregiver may be a crisis with an underlying opportunity, a better outcome for the cancer patient; Barker's fourth assumption. Week two content module was *Cancer Terminology*. This is supported by Barker's second assumption of the model, recognizing resourcefulness. By having the resources available caregivers can educate themselves further on terminology they might not understand. Week three content, *Symptoms of Treatment and Management* supporting Barker's fourth and fifth assumptions of the model; accepts that a crisis is an opportunity, and all goals must belong to patient respectively. Week four content *Caring for the Caregiver* is supported by the sixth assumption, the simplest means should be sought out. Week five material, *End of Life Considerations,* is endorsed with the third and fifth assumptions, respect for patient’s wishes and all goals must belong to the patient, respectively. This content was presented to the cancer caregiver to support end-of-life care for the cancer patient. Tools and resources were provided for the cancer caregiver to navigate these tough decisions. Week six was a time allowed for final discussions, concerns, and fellowship with other cancer caregivers. The ZCBA tool post measures were collected at that time.

This project was offered in person and online with a DNP student facilitator. In-person sessions were recorded for future use. This creates a simple scenario for the cancer caregiver to participate in the intervention and learn caregiver care techniques; potentially never leaving their home. In addition, multiple modalities are suggested by the review of literature as having superior outcomes.

This DNP project demonstrated inclusivity with a focus on education of a diverse population of cancer caregivers within the city of Louisville, KY. Gilda’s Club has two locations, one in St. Matthews (east side of town) and Gilda’s West, located in the west end of the city. This project was committed to inclusivity of all caregivers and provide them with education through the partnership with Gilda’s Club. This DNP student anticipated a minimum of thirty participants in this program, however, impacted seven participants during the study. The inclusion criteria were that the participant is an adult and caregiver of a cancer patient actively going through treatment or a cancer survivor. A marketing campaign was implemented to recruit cancer caregiver participants for this project. The weekly sessions were placed on the monthly calendar of activities for Gilda’s Club which is also on their website. (Gilda’s Club Kentuckiana, 2023).

This DNP student hypothesized that the root cause of caregiver burden is lack of knowledge. Through this program's implementation, the intent was to address the knowledge deficits and decrease perceived caregiver burden. The main stakeholder in this project was cancer caregivers. The intent was to positively impact their experience of providing care for the cancer patient or survivor. An additional stakeholder indirectly impacted was the cancer patient or survivor. Their care will now be provided by a caregiver with increased knowledge regarding cancer and cancer care. A champion stakeholder was the Program and Impact Officer at Gilda's Club. She had an elevated level of desire in providing additional opportunities to enrich the programs offered by Gilda's Club. This program can serve as a flagship program for future caregiver programs. The executive board members of Gilda's Club were all considered stakeholders. Finally, additional stakeholders in the project were the members of this student's DNP committee.

Cultural Barriers

The DNP project took place at a community-based center. Louisville is a diversified city. Cultural awareness was a priority for this DNP student given the variety of languages and cultures have potential for representation. Language barriers were considered first. Those participants with a language barrier were identified during recruitment on the demographic questionnaire.

Other aspects of cultural awareness were implemented by the DNP student include being aware of own cultural biases, nonverbal clues, and respect and openness about culture. Different cultures have differed responses to illness. In some cultures, some caregivers may not want to participate in any discussions. In others, the women provide all the household coordination. Thus, if that woman is sick, the dynamics change. There are also cultures with caregivers that either do not recognize the need for assistance or do not feel comfortable asking for help. This leads pride-related issues influenced by culture. Socioeconomic status (SES)is a barrier. Those with lower SES have less time to participate in support groups or other time to dedicate to any other interventions. Consideration was given to transportation issues; caregivers might not have reliable transportation to either location of Gilda's Club. Given this program has an on-line option, this will increase access given that the participant does have internet.

Ethical Considerations/ Permissions

This project proposal was submitted to the University of Louisville Internal Review Board (IRB) for approval prior to implementation. The Program and Impact Officer for Gilda's Club provided a letter granting permission for the project to be completed at this facility. Caregivers' data was be de-identified and all data was stored in a secure file in the DNP student's encrypted computer that always remain locked.

Procedure/Interventional Plan

After appropriate IRB at the University of Louisville and the Program and Impact Officer at Gilda's Club approval was obtained, a description of the weekly session offering was placed on Gilda's Club site. This was developed by Gilda's Club marketing division and approved by the Program and Impact Officer. This included not only a description of the program, but background information, goals of the program, dates, times, location, and Zoom option for each session. The description contained a phone number for the participants to register directly at Gilda's Club and the DNP student contact information. The descriptions were advertised on their monthly activity calendar at the facility and online. This occurred in December 2023. At the time of registration, the patient's name, phone number, and email address were collected. The program kicked off the second week January 2024, at St. Matthew's location of Gilda's Club. This program continued Thursday nights in 1730 for 60 minutes for the next five weeks. Each live session was accessible through Zoom via Gilda's Club. All materials were printed in the participants preferred language using simple language and no medical jargon. A link was emailed to participants attending all informational materials for that week's session.

The initial group meeting addressed the following objectives: a.) the participants will understand of the impact of being a caregiver of a person with cancer, b.) the participants will comprehend how the Zarit Caregiver Burden Assessment (ZCBA) tool is utilized, and c.) explanation of consent process to proposed project participants. All data from project participants was collected in a format that does not identify the participant using the link from Microsoft Forms. Their phone number in the form of “000-000-0000” was the identifier used on all documents for anonymity. These were stored in Microsoft Forms. After informed/implied consent was obtained, demographic data was collected using the same process. Demographics included age of cancer caregiver, age of the cancer patient, relationship to person with cancer, gender identification (male/female/non-binary/prefer not to answer), preferred language, the cancer diagnosis, how many years served as caregiver, and if there is a support system as primary caregiver. Zoom participants received the same link and it was emailed to them at the completion of the presentation. Those participants remained on Zoom if technical assistance was needed. Administration of the ZCBA occurred in the same manner. The remaining 20 minutes was allotted for a question-and-answer session for the caregiver participants. Each weekly module was developed using simple terminology and avoided medical jargon given that the average reading level in Kentucky is about the 8th grade. (NAEP *state profiles*, 2022).

The presentation format for the following four weeks was presented in the same manner. There was an in-person meeting at Gilda’s Club with a Zoom option with an interactive PowerPoint presentation for 40 minutes with 20 mins for questions and discussions. All materials were emailed to the Zoom participants prior to the meeting. All content was verified by the expertise of the Program and Impact Officer of Gilda’s Club.

The week two session included an interactive discussion and PowerPoint regarding typical cancer terminology. This module was developed using the cancer terminology directory from the National Cancer Institute (NCI) (NCI, Dictionary of Cancer terms, 2023).

The week three session included an interactive discussion and PowerPoint presentation regarding typical treatment symptoms associated with treatment and their management. This module was developed using the Advanced Oncology Certification Review and Resource manual (Saria et al., 2023) and resources from the NCI website (NCI, side effects, 2023).

The week four session included an interactive discussion and PowerPoint presentation on information surrounding caregiver mental health, verified by content expert Dr. Kate Adelstein, at the Grinstead location of Gilda's Club. After the interactive presentation Dr. Kate Adelstein, DNP committee member, provided instruction on stress relieving deep breathing techniques.

The week five session included an interactive discussion and PowerPoint presentation that was presented regarding end-of-life considerations including information on power of attorney.

The last session, week six, was considered the wrap up group meeting. The ZCBA tool was administered via a link via Microsoft forms to each participant. Their participant's identification will remain the same as on the pre-program Zarit assessment. After the end of the program, the DNP student lead left contact information for any further assistance. The student coordinated with the Program and Impact Officer to have content (PowerPoint presentations and recordings of sessions) uploaded to Gilda's Club website to ensure the programs sustainability.

Fiscal Inputs and Resources

There were costs associated with implementing this project. According to Baker et. al., (2018), there are two types of costs; indirect and direct. An indirect cost is "allocated to a certain cost object" or associated with the entire operation and a direct cost is "traced to a cost object" or incurred for the sole benefit of a particular operating unit (p.55). Indirect costs that were associated with this DNP project were utilization of the Gilda’s Club physical building and the overhead costs associated with operations. Additional indirect costs include what the organization incurs for Zoom, website access, and maintenance. This project used Gilda’s Club’s existing accounts access for this part of the project. The time of the participants, cost of transportation, or the cost of internet access for the Zoom meetings are also indirect costs associated with the project. Direct costs associated with this DNP project include the DNP students time used to develop the weekly modules, the Program and Impact Officer’s time allocated to validating the program’s content, implementation, and miscellaneous supplies such as office supplies. The implementation entails the development of the links for in person or Zoom meetings (labor), printed handouts, distribution of the handouts, signup links, links for demographic data collection and the Zarit tool utilizing Microsoft Forms. Additionally, there is cost associated with SPSS for analyzing the data.

Measures

The intended outcome of this DNP project was to decrease caregiver burden. This was measured utilizing the ZCBA (12-item) tool. This was administered prior to the educational intervention and at the program’s completion. The results of this were analyzed through the statistical testing in Excel. Each pre and post assessment tool was numbered to correspond with the caregiver’s phone number.

The ZCBA tool does not require permissions to use as students and non-funded academic users can access this tool online. The Zarit Caregiver Burden Interview originated as “29-item questionnaire” (APA, 2011). There have been several revisions and the tool has been translated to several different languages as well. The original studies use this tool for caregivers of dementia patients but it has been adapted to the oncology population in recent studies. Higginson et al., (2010), studied six short versions of the Zarit Burden Interview (12-item,8-

item,7-item,6-item,4-item, 1- item) across three caregiving populations, including those with advanced cancer.

> “All short-form versions, except the ZBI-1 in advanced cancer (rho=0.63), displayed good correlations (rho=0.74-0.97) with the ZBI-22. Cronbach's alphas suggested high internal consistency (range: 0.69-0.89) even for the ZBI-4. Discriminative ability was good for all short forms (AUC range: 0.90-0.99); the best AUC was for ZBI-12 (0.99; 95% confidence interval [CI]: 0.98-0.99) and the second best for ZBI-7 (0.98; 95% CI: 0.96-0.98) and ZBI-6 (0.98; 95% CI: 0.97-0.99)” (Higginson et al. ,2010).

This study demonstrated that all different variations of the shorter version of the Zarit Burden Interview possess “very good validity, internal consistency, and discriminative ability” however, the twelve-item version is superior. (Higginson et al., 2010). This DNP project utilized the 12-item questionnaire. Each of the twelve questions evaluated on a five-point Likert scale from 0 (never) to 4 (nearly always) (APA, 2011). According to Zarit et al. (1980), the summed score can range from zero to 48 with the twelve-item version. With these scores, zero to ten total score means that none or mild burden is present, ten-twenty means that mild to moderate burden is present, and any score above twenty proves high burden is present.

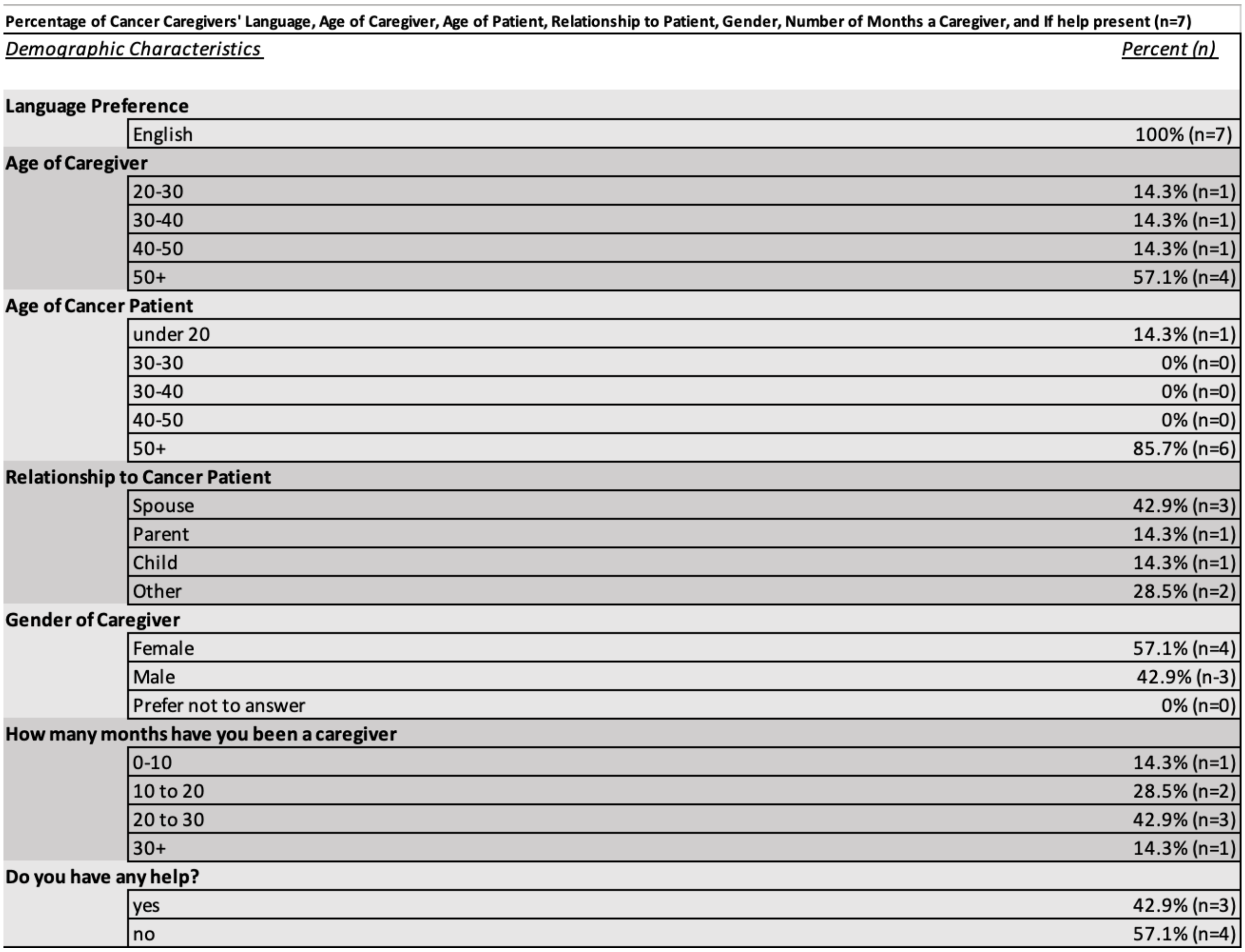
Intervention Implementation

Beginning in late December 2023 marketing was done by placing a description of program on the online calendar for Gilda’s Club. This calendar is the main source where participants of Gilda’s Club find out about the various programs that are offered. This description was placed on the January calendar starting on January 18,2024. There was a total of nine participants in the program, with seven pre-Zarit Caregiver Burden Assessment answers and four post- Zarit Caregiver Burden Assessment answers. During the first week there were three registrations virtually. This student attended virtually. There were no participants that showed up at our specified time, in person or virtually. The moderator from Gilda's Club was late as well. The Program and Impact Officer was contacted and issues of the week were discussed. A specific delegate at Gilda's Club was assigned to the education intervention going forward. A flood occurred after week one of the intervention displacing Gilda's volunteers and caused cancellations and rescheduled programs. During the second week of the program, January 25,2024 this student attended at Gilda's Club. Time was allotted for participants to complete demographics form and the pre Zarit Caregiver Burden Assessment form after consents were explained prior to beginning the Week two material. Week two had one participant in person and seven on Zoom. These participants were also given information form week one. Week three had two participants on zoom. There was one brand new participant, weeks one and two materials were reviewed prior to beginning week three material. Week four there was one participant on zoom and one participant in person. Week five there were two virtual participants and week six there was one virtual participant. Weeks four through six went on as planned with this student in attendance at Gilda's Club to conduct the program, no deviations from the planned topics occurred. After the program was completed the email list of participants was obtained and the post- Zarit Caregiver Burden assessment link was sent over the next three weeks. Overall, demographics were collected on seven participants, with only four participants completing the pre and post assessments. A portion of the participants from week two did not fill out the demographics, pre, or post assessment and were therefore lost to follow-up.

Data Analysis

Demographic data was collected through Microsoft Forms for all initial participants including language preference, caregiver age, age of cancer patient, diagnosis of cancer patient, relationship to cancer patient, gender of caregiver, how many months have you been a caregiver, and lastly if there is anyone to help. These demographics were collected in the second week as there were no participants week one. These simple descriptive statistics were run in Microsoft excel. The mean caregiver age was 49.29 years of age, with a range of 41 years, a median of 54 years of age, and no mode. The mean age of cancer patient was 58.71 years of age, with a range of 75 years, a median of 65 years, and a mode of 78 years of age. The diagnoses of the patients covered all different types including; ovarian cancer, two participants with lung cancer, one with metastatic, a patient with both breast and stomach cancer, stage 4 neuroendocrine cancer, Chronic Lymphocytic Leukemia, and an atypical rhabdoid tumor. There were three spouses, two mothers, one daughter in law, and one grandmother. When months as a caregiver was examined, the mean was 44.43 months, with a median and mode of 24, the range was 182 months. There was an outlier of 192 months within the data.

Figure 1 *Percentage of Language, Age, Relationship, Gender, Months a Caregiver, and if help present*

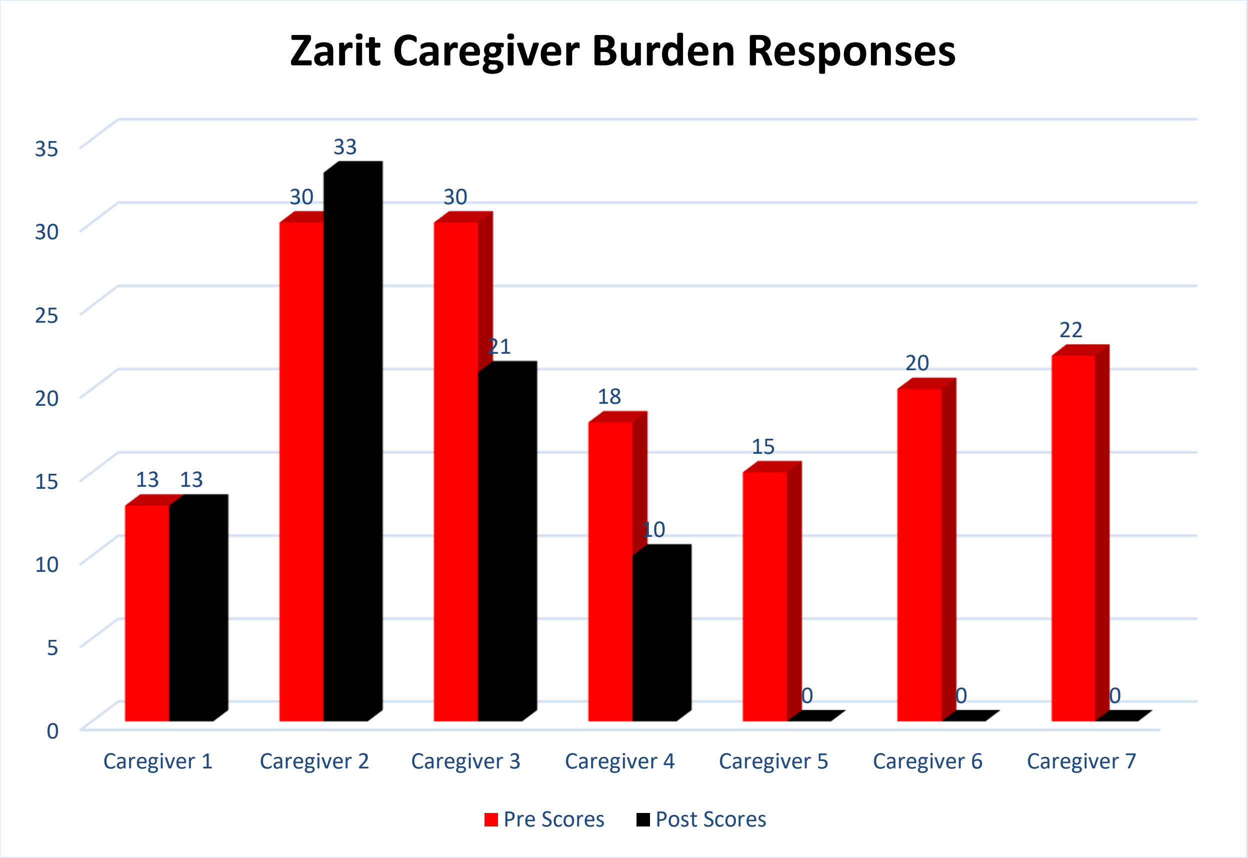


Percentage of Cancer Caregivers' Language, Age of Caregiver, Age of Patient, Relationship to Patient, Gender, Number of Months a Caregiver, and If help present (n=7)

Demographic Characteristics		*Percent (n)*
Language Preference		
	English	100% (n=7)
Age of Caregiver		
	20-30	14.3% (n=1)
	30-40	14.3% (n=1)
	40-50	14.3% (n=1)
	50+	57.1% (n=4)
Age of Cancer Patient		
	under 20	14.3% (n=1)
	30-30	0% (n=0)
	30-40	0% (n=0)
	40-50	0% (n=0)
	50+	85.7% (n=6)
Relationship to Cancer Patient		
	Spouse	42.9% (n=3)
	Parent	14.3% (n=1)
	Child	14.3% (n=1)
	Other	28.5% (n=2)
Gender of Caregiver		
	Female	57.1% (n=4)
	Male	42.9% (n-3)
	Prefer not to answer	0% (n=0)
How many months have you been a caregiver		
	0-10	14.3% (n=1)
	10 to 20	28.5% (n=2)
	20 to 30	42.9% (n=3)
	30+	14.3% (n=1)
Do you have any help?		
	yes	42.9% (n=3)
	no	57.1% (n=4)

When analyzing the data obtained for the Zarit Caregiver Burden Assessment tool through Microsoft forms. Simple descriptive statistics were run using excel. There were only four data points to examine for pre and post data as the rest were lost to follow up.

Figure 2 *Zarit Caregiver Burden Responses*



The pre-program scores had a mean of 22.75, a median of 24, a mode of 30, with a range of 17. The post- program scores had a mean of 19.25, a median of 17, there was not a mode, and a range of 23. The original intention was to perform a paired *t-Test* given the paired data however the five assumptions in order to use this test were not met. Given that the five assumptions did not hold true a non-parametric equivalent test, the Wilcoxon Signed-Ranks test was run. Unfortunately, when comparing the alpha level (0.05) and sample size of three. There was no value on the tablet that correlated. Thus, concluding the sample size was too small to complete this test.

This DNP lead then compared the percentage of sessions attended by the caregivers with their percentage change in scores.

Figure 3 *Percentage of Sessions Attended*

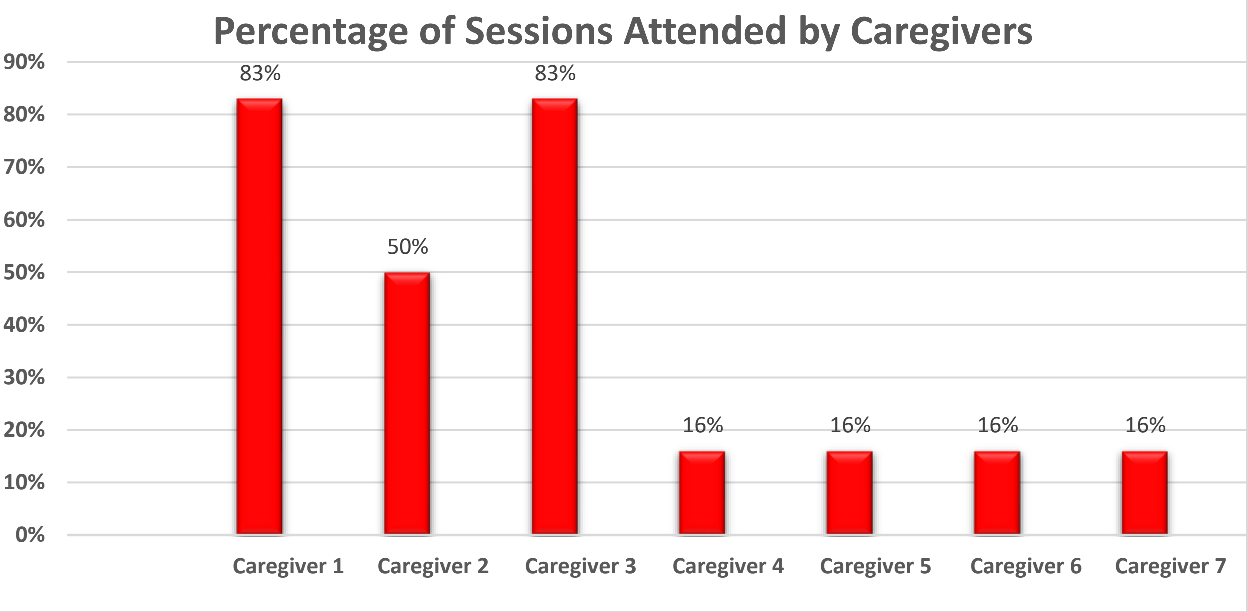
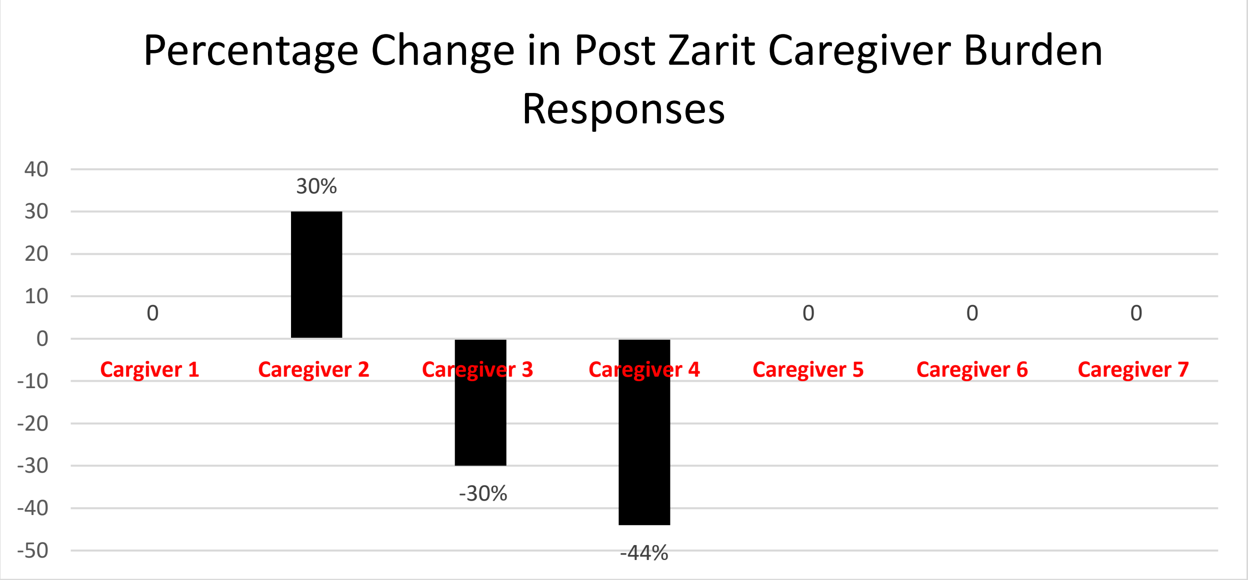


Figure 4 *Percentage Change in Zarit Caregiver Burden Responses*



Caregiver one demonstrated a 0% change in their pre and post Zarit scores. Caregiver two demonstrated a 30% increase in their post Zarit score. Caregiver three demonstrated a 30% decrease in their pre and post Zarit scores. Caregiver four demonstrated a 44% decrease in their pre and post Zarit scores. Caregivers five through seven did not have a post score therefore did not experience any change. Both caregiver three and four demonstrated a decrease in their scores however when comparing attendance had very different attendance, five sessions and one session respectively. Caregiver one has one of the highest session attendances however did not have a change in pre and post scores. An inference cannot be made about a correlation between attendance and scores. The caregiver that experienced the increase in score reported external stressors during the program, these were not items that could be addressed. Percent decrease in scores despite attendance could be attributed to the fact that participants were emailed each session PowerPoint for review on their own. Participants were given DNP lead's email for questions if review was mainly on their own time.

Discussion of Intervention

The results this program did not align with the attendance expectations. Therefore, upon review of data obtained from this study, no statistical test (*t*-test or non-parametric equivalent) were able to be performed due to a small sample size. Simple statistics and percent changed were performed on data that was provided. Upon reevaluation of the program several reasons were considered.

To begin with, examining the time at which the programs was offered. Reviewing the calendar for Gilda's Club there were several programs offered prior to and after the caregiver program offered by this DNP lead. Perhaps due to this, the appropriate attention was not given to the program. Gilda's Club did have a malfunctioning sprinkler system during the program offering that resulted in a massive flood in the center that potentially impacted week two when additional advertising was to occur. Gilda's Club was required to cancel programs due to the flood. When speaking with the Program and Impact Officer this could have contributed to low attendance for the program. The nightly support groups at Gilda's Club are typically quite full, it is possible that caregivers did not have the time to commit to another night of attending a program.

Another possibility to consider is the caregivers' commitments to the cancer patient. If a caregiver attends a program in the evening, the cancer patient is left without a caregiver at home. A caregiver in this student's session did mention that the virtual option was chosen because the patient that they were caregiving for would not allow a different person to care for them. Session timing other than winter could possibly have yielded better attendance. Most attendance was virtually so participants did not have to travel so it is unknown if the cold weather was a huge impact for the attendance of the program. This student could consider offering the program at an earlier point in the day, the original time was used as to not interfere with potential oncologist appointments.

More advertising may have been helpful prior to the program. Flyers placed at local cancer centers and at both locations of Gilda's Club may have reached more caregivers. This was not done initially because when the original needs assessment was completed, historically a large turnout always occurred. Thus, only a description of the program was listed on the website of Gilda's Club. During the program participants needed to register for each week, and this could have contributed to low weekly numbers as caregivers might have forgotten to do this. Gilda's Club stated that they would email participants to remind them each week, through talking with participants and this was not done.

Future Implications

Do caregivers recognize the need for self-care or any further education regarding what they are "expected" to do? According to Wittenberg et al. (2023), "cancer caregivers reported higher unrecognized-demanded information states (i.e., not recognizing information was needed), more communication confidence, and more frequent caregiver assessment". This article also explores different types of caregivers, including a "manager caregiver type" and a "lone caregiver type". Wittenberg et al. further discussed that based on the type of caregiver one is, drives the communication or recognition for assistance. If this project was to be reworked again, a question regarding caregiver type could be added to the demographic questions. Given the low attendance of the module sessions during the project, it could be presumed that caregivers do not recognize the additional needs that they have.

In addition, perhaps this program could have been broken up differently. The program could have been offered into one to two sessions and have the sessions longer in length. Originally, the program was structured with only one-hour sessions out of ease for caregivers to attend for a short amount of time, however it might make it easier on the caregiver to find another person to help out with their duties only once or twice as opposed to six times, despite the length of the session.

Conclusion

With the advent of new therapies directed at treating cancer, shifting caregiving from hospitals and other traditional locations to outpatient areas and the home, there is also a shift in the amount of burden placed on the responsible party of that patient. While this is beneficial for the cancer patient, it places an increased burden on caregivers, most of whom are not medical professionals. This often leads to increased burden. Emerging research is addressing the caregiver experience. Although eliminating burden completely is not a possibility, there is a need to augment the caregiver experience for that would only improve upon patient outcomes. This DNP project sought to lead to increased knowledge in caring for cancer patients, thus removing sources of stress for those caregivers. Caregivers do not always recognize that they need support. This was reflected in the low attendance and sample size of the project. Gilda’s Club did not expect low attendance, however as stated previously they have never had a program specific to caregivers. As more interventions similar to this get developed there might be higher attendance. A potential separate intervention could address how to impact caregiver recognition of need as that might be the direction that first needs to be addressed prior to providing education for caregivers.

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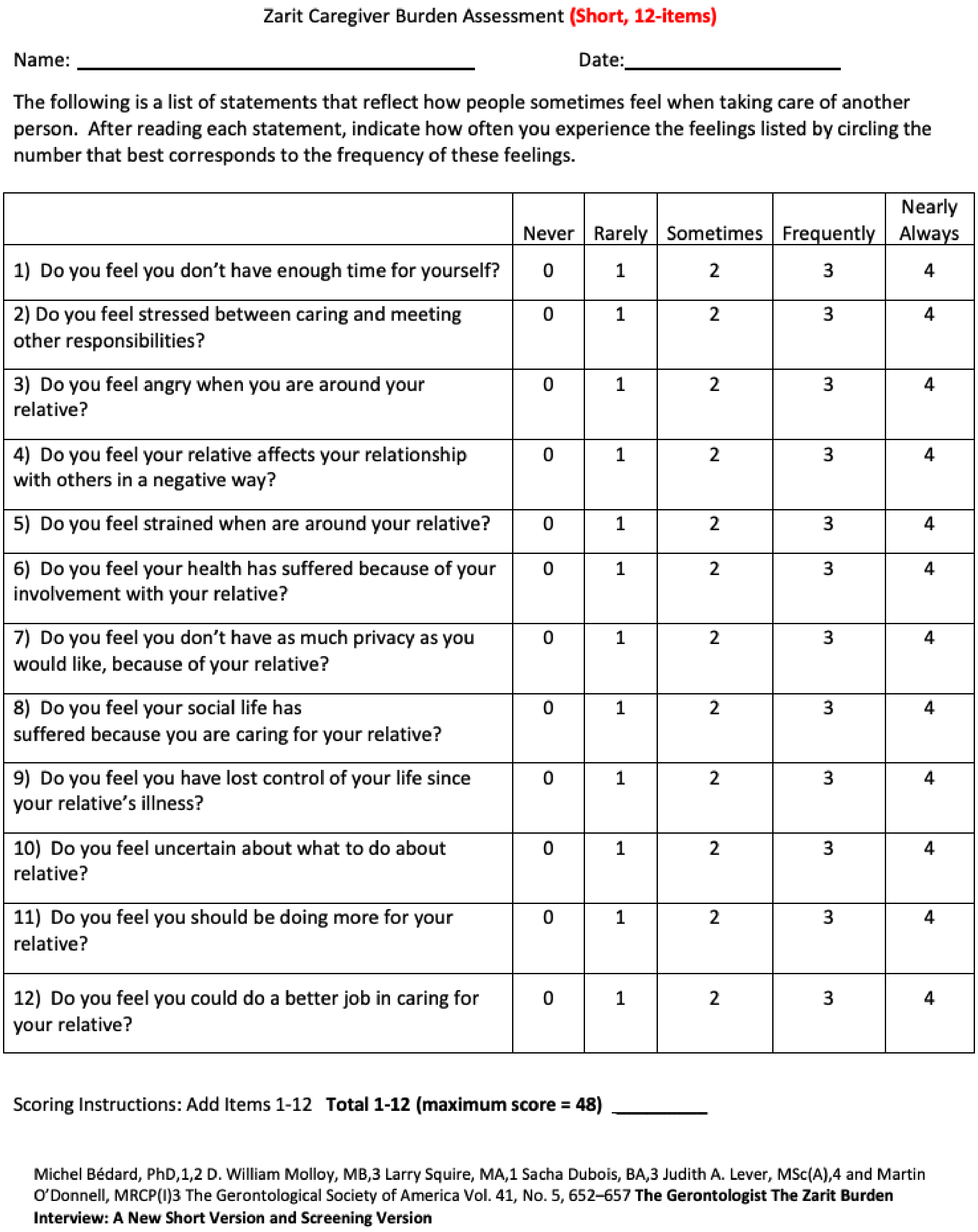
Appendix A: Zarit Caregiver Burden Assessment (12-item)



Zarit Caregiver Burden Assessment **(Short, 12-items)**

Name: ________________________________ Date:________________

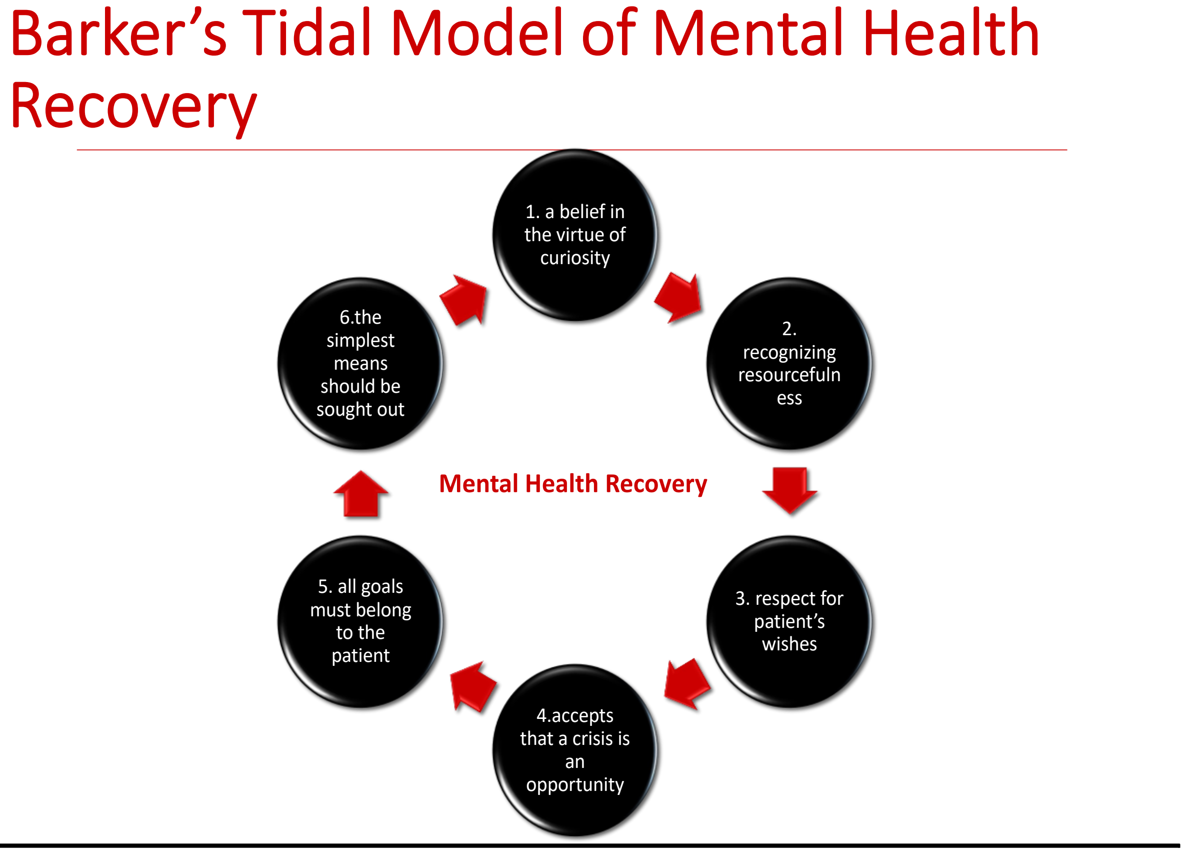
The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Frequently	Nearly Always
1) Do you feel you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring and meeting other responsibilities?	0	1	2	3	4
3) Do you feel angry when you are around your relative?	0	1	2	3	4
4) Do you feel your relative affects your relationship with others in a negative way?	0	1	2	3	4
5) Do you feel strained when are around your relative?	0	1	2	3	4
6) Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) Do you feel you don't have as much privacy as you would like, because of your relative?	0	1	2	3	4
8) Do you feel your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about relative?	0	1	2	3	4
11) Do you feel you should be doing more for your relative?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

Scoring Instructions: Add Items 1-12 **Total 1-12 (maximum score = 48)** __________

Michel Bédard, PhD,1,2 D. William Molloy, MB,3 Larry Squire, MA,1 Sacha Dubois, BA,3 Judith A. Lever, MSc(A),4 and Martin O'Donnell, MRCP(I)3 The Gerontological Society of America Vol. 41, No. 5, 652–657 **The Gerontologist The Zarit Burden Interview: A New Short Version and Screening Version**

Appendix B: Barker's Tidal Model of Mental Health Recovery



Barker's Tidal Model of Mental Health Recovery

Mental Health Recovery

1. a belief in the virtue of curiosity
2. recognizing resourcefulness
3. respect for patient's wishes
4.accepts that a crisis is an opportunity
5. all goals must belong to the patient
6.the simplest means should be sought out

Appendix C: Demographic Information Form

Participant #: __________

Language Preference: _______________

Caregiver Age: ___________

Age of cancer patient: _____________

Diagnosis of cancer patient: _____________

Relationship to cancer patient: ______________

(examples include: spouse/partner, child, other family member, or friend)

Gender of caregiver: ***(please circle one)***

Male

Female

Non-binary

Prefer not to answer

How many years have you been a caregiver for this patient? ___________________

Do you, as a caregiver, have anyone to help you? ***(please circle one)***

yes or no