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Addressing Caregiver Burden: Program Development to Improve the Quality of Life of Caregivers of Cancer Survivors

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A Capstone Project Entitled

Addressing Caregiver Burden: Program Development to Improve the Quality of Life of Caregivers of Cancer Survivors

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Abstract

The purpose of this Doctoral Capstone Experience (DCE) was to create a one time, educational session, “Caring for those who Care,” for caregivers of cancer survivors at the Indianapolis chapter of Cancer Support Community (CSC). CSC staff completed a self-created needs assessment survey and caregivers completed the Caregiver Quality of Life-Cancer (CQOL-C) and Zarit Burden Interview (ZBI) to determine current barriers encountered by caregivers. The DCE student utilized thematic analysis to analyze needs assessment results, evidence based literature, and interactions with CSC staff and caregivers to develop and implement “Caring for those who Care.” Prior to beginning “Caring for those who Care,” participants completed the CQOL-C, ZBI, and a self-developed pre-survey. Five participants, three caregivers and two CSC interns, attended the session, which covered an educational and discussion portion for four topic areas: self-care, stress management, fatigue management, and anticipatory grief. Immediately following the session, participants completed a self-developed post-survey to determine knowledge gained. Two weeks following the session, participants completed the CQOL-C and ZBI to determine changes in quality of life (QoL) and burden. Despite inconclusive data on improvements in QoL and burden due to environmental barriers for two of the three caregivers in attendance, results indicated an improvement for 100% of participants in knowledge gained and improvements in implementation of strategies and skills for fatigue and stress management, self-care, and anticipatory grief. Overall, results indicate “Caring for those who Care” was successful and would be beneficial to continue to offer for caregivers of CSC.

Keywords: caregivers, cancer, survivors, quality of life, burden, occupational therapy, community setting, Caregiver Quality of Life-Cancer, Zarit Burden Interview

Literature Review

In 2015, there were approximately 3 million caregivers caring for individuals with cancer within the United States (National Alliance for Caregiving, 2015). An individual is considered a caregiver if he or she is providing care to one who needs assistance completing daily activities, due to disability or chronic illness (National Cancer Institute, 2014a). Although more individuals are being diagnosed with cancer each year, with 1.7 million new cases of cancer diagnosed in 2018 within the United States alone, the number of cancer-related deaths is decreasing and the number of survivors is increasing (National Cancer Institute, 2018). In 2016, there were approximately 15.5 million cancer survivors and that number is expected to grow to 20.3 million by 2026 within the United States (National Cancer Institute, 2018). An individual is considered a cancer survivor from diagnosis until the completion of life, with caregivers included as a cruicial element of survivorship (National Cancer Institute, 2014b). As the number of cancer survivors continues to grow, so will the need for caregivers, as well as the need to assess the impact of caregiving on these individuals (National Cancer Institute, 2016).

Cancer Caregiver Demographics

The demographics of caregiving have shifted from professional caregivers to family members as a result of a reduced duration of time spent at the hospital (Tan, Molassiotis, Lloyd Williams, & Yorke, 2018), with a staggering 88% of 111 cancer caregivers providing care for relatives (National Alliance for Caregiving, 2016). The average age of caregivers is approximately 53 years old, with 58% of caregivers being women (National Alliance for Caregiving, 2016). Cancer caregivers spend approximately 33 hours a week providing assistance to loved ones with Activities of Daily Living (ADLs), such as bathing, toileting, dressing, and hygiene, as well as asssitance with Instrumental Activities of Daily Living (IADLs), including driving, financial management, medication management, and shopping (National Alliance for Caregiving, 2016). In addition to physical support, caregivers reported providing emotional, financial, spiritual, and social support throughout the duration of cancer treatment (Ahmad & Khan, 2018).

Caregiver Burden

Cancer caregivers are unique because their role of caregiving, although somewhat brief compared to caring for other individuals, is *very intense,* due to the large quantity of responsibilities and hours spent caring (Lapid et al., 2016, p.1400; National Alliance for Caregiving, 2016). Approximately 86% of 188 caregivers of individuals with a variety of cancer diagnoses reported their needs were unmet, highlighting a lack of information provided on their loved one's disease progression, difficulty balancing their loved one's needs with their own, as well as lack of emotional and psychological support (Lapid et al., 2016; Sklenarova et al., 2015). Many family caregivers begin their caregiving duties without training (Almutairi, Alodhayani, Alonazi, & Vinluan, 2017), as evidenced by 43% of cancer caregivers completing complicated medical tasks without prior instruction, such as administering medication, determining whether medicine is necessary, and changing bandages (National Alliance for Caregiving, 2016; Van Ryn et al., 2011). As a result of daily care responsibilities and lack of support and training, caregivers are experiencing caregiver burden, defined as physical, emotional, psychosocial, and financial burden (Tan et al., 2018). Pain, fatigue, weakness, sleep disturbance, anxiety, and depression were among the most commonly reported ailments related to caregiver burden (Tan et al., 2018). Chronic stress also burdens caregivers, initially negatively impacting their psychological health and overtime impacting their physical health (Ahmad & Khan, 2018). These burdens can lead to increased distress, followed by reduced mental health and quality of life, which is defined as an individual's social, physical, and emotional health domains (Almutairi et al., 2017; Kai Ting Chua et al., 2016). A decreased quality of life for caregivers not only negatively affects the caregivers themselves, but also extends to the survivor's quality of life and the healthcare system as a whole (Romito, Goldzweig, Cormio, Hagedoorn, & Andersen, 2013; Tan et al., 2018). If caregivers are able to provide ideal care, then their personal burden and strain on the healthcare system is reduced, which ultimately improves the survivor's outcomes (Shin et al., 2018). Therefore, there is a dire need for education and counseling programs, as the burden associated with the role of primary caregiving for a cancer survivor is expected to increase for middle and older adults by 2030 (Almutairi et al., 2017).

Role of Occupational Therapy

Caregiving, or care of others, is defined as an IADL within the Occupational Therapy Practice Framework (OTPF) and is within the scope of practice for occupational therapy practitioners (American Occupational Therapy Association [AOTA], 2014). As previously mentioned, the literature suggests caregivers are struggling to meet their own needs, along with the needs of those they are caring for (Grimm & Schmid, 2018). The needs of caregivers are often overlooked and the survivor's needs are put first (Almutairi et al., 2017; Tan et al., 2018). Therefore, there is a necessity for practitioners to develop tailored interventions to facilitate balance of personal and caregiving responsibilities (Grimm & Schmid, 2018). Due to their education and training, "occupational therapy practitioners are situated to develop interventions that meet the comprehensive needs of caregivers" (Grimm & Schmid, 2018, p. 1). There is increasing support for reimbursable interventions within the occupational therapy (OT) scope of practice, including education, training, and provision of strategies to encourage occupational performance and caregiver well-being (Piersol et al., 2017). Research suggests education and support for caregivers should be integrated into cancer survivor's discharge plans (Romito et al., 2013). Although these interventions are applicable in a variety of practice settings (Piersol et al., 2017), occupational therapists need to move beyond the acute phase of survivorship and begin addressing the long-term impacts of cancer within the community setting (Polo & Smith, 2017). The thoughts of Polo and Smith also applies to the needs of caregivers.

Theoretical Background

The Ecology of Human Performance (EHP) model can be used as a lens to better understand the role of OT in meeting the unmet needs of caregivers of cancer survivors and decreasing caregiver burden. The EHP focuses on the impact of one's environment on task performance (Cole & Tufano, 2008). Environment is defined as one's physical, social, cultural, and temporal context, and task is defined as preceding steps to occupations or roles (Cole & Tufano, 2008). Caregivers' unique skill sets and characteristics are negatively impacted by the contextual factors associated with caregiving (Tan et al., 2018), which in turn negatively impacts their occupational performance and fulfillment of roles (Grimm & Schmid, 2018). A few of the contextual factors influencing caregiver burden include specific cancer diagnosis and duration of hospitalization of the cancer survivor, education provided on diagnosis presentation and prognosis, survivor's estimation of burden on the caregiver, and the physical and mental health of both the caregiver and survivor (Ahmad & Khan, 2018; Shin et al., 2018; Tan et al., 2018). Social supports from family and friends, as well as financial resources, are also important contextual factors to consider (Maguire, Hanly, Hyland, & Sharp, 2018).

There is a need for OTs to support caregivers with appropriate interventions due to the negative influences the context of caregiving has on caregivers' ability to successfully perform their self care tasks and ultimately their meaningful occupations (Grimm & Schmid, 2018).

Therefore, the purpose of this project was to design and implement an occupation based program to improve the quality of life of caregivers caring for survivors in the community setting.

Needs Assessment

In order to design an effective program to improve quality of life for caregivers caring for survivors, a thorough needs assessment was conducted. Using the EHP model as a guide to determine contextual barriers impacting caregivers' task performance (Cole & Tufano, 2008), caregivers at Cancer Support Community (CSC) were asked to complete two assessment tools, the Caregiver Quality of Life Index-Cancer (CQOL-C) questionnaire and the Zarit Burden Interview (ZBI).

Tool & Survey Descriptions

The CQOL-C, which can be referenced in Appendix A, was an appropriate and useful assessment tool for this needs assessment because it goes beyond general quality of life (QoL), and specifically applies to caregivers of individuals with cancer (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999a). The CQOL-C is a 35 question assessment designed to measure the QoL of family caregivers of cancer survivors, generalizable to various types of cancer diagnoses (Weitzner et al., 1999a). The CQOL-C asks caregivers of cancer survivors to indicate how true each statement has been for them within the past week, ranging from not at all (0) to very much (4) (Weitzner et al., 1999b). In addition to excellent internal consistency and test-retest reliability, the CQOL-C exceeds validity and reliability psychometric criteria (Edwards & Ung, 2002, p.342; Weitzner et al., 1999a, p.62).

The full form ZBI is one of the frequently used tools to assess caregiver burden and has been used in a variety of settings (O'Rourke & Tuokko, 2003, p. 121). The ZBI short form, which can be referenced in Appendix B, is a 12 question assessment of subjective burden, with the goal of measuring the impact of the role of caregiving on the lives of caregivers (Bédard et al., 2001a). The ZBI asks caregivers to indicate how often they feel a certain way, ranging from never (0) to nearly always (4) (Bédard et al., 2001b). The shortened ZBI was an appropriate assessment tool and supplement to the CQOL-C for this needs assessment because it required less time to complete and does not reduce the reliability and validity of the original ZBI (Bédard, Molloy, Squire, Dubois, Lever, & O'Donnell, 2001; O'Rourke & Tuokko, 2003).

Staff at CSC who work directly with caregivers were asked to identify barriers impacting task performance for caregivers utilizing a survey generated from themes from the literature, which can be found in Appendix C. The survey questions created for staff were developed through the lens of the EHP, with the goal of evaluating contextual factors influencing caregiver burden (Cole & Tufano, 2008). A survey was utilized because it is an appropriate method of gathering data in the community setting (Stein, Rice, & Cutler, 2013). Stein, Rice, and Cutler (2013) note survey research can be applied to multiple community health services, specifically designing preventative health, therapeutic, or educational programs within the community. This coincides with the purpose of this program, which was to design and implement an educational program in the community setting to improve the QOL of caregivers caring for cancer survivors.

Generation of Themes

Needs assessments were conducted and themes were generated until saturation was reached, or when no new categories or themes were generated (Corbin & Strauss, 2006). Themes from the staff and caregiver’s questionnaires were generated utilizing thematic analysis, the process of identifying, analyzing and reporting patterns within data (Braun & Clarke, 2006, p. 79). Thematic analysis is an adaptable, valuable form of analysis, which has been shown to generate a comprehensive and multifaceted interpretation of a set of information (Vaismoradi, Turunen, & Bondas, 2013). In addition to thematic analysis, an analysis of CSC's strengths, weaknesses, opportunities, and threats (SWOT) was completed in regards to caregiver programming and resources, found in Appendix D. The SWOT analysis provided a better understanding of the opportunities to improve caregivers' QOL within this community setting prior to constructing a program (Bonnel & Smith, 2018).

Results

The CQOL-C and ZBI were completed with six caregivers of survivors; however, due to contextual details surrounding one individual's experience with caregiving, this individual's responses were deemed inappropriate for the purpose of this program and were not included during thematic analysis. Five main themes emerged from the CQOL-C and ZBI, including increased stress and mental strain, less restful sleep, financial strain, fearing adverse effects of treatment and death on their loved one, and distress associated with watching their loved one deteriorate. The details of these results are listed below, as well as in Appendix E.

Eighty percent of caregivers reported increased stress and worry associated with caregiving, ranging from quite a bit (3) to very much (4), and 100% of caregivers reported increased mental strain, with 60% indicating very much (4) increased mental strain. One individual emphasized that her own health was suffering because she "tends to ignore her own needs." One hundred percent of caregivers reported less restful sleep, with scores ranging from (2) somewhat to (4) very much, and one individual shared she was feeling a "level of exhaustion she never knew existed, physically and mentally." Another individual noted, "A program covering how to have more energy would be extremely helpful." One hundred percent of caregivers reported financial strain, ranging from a little bit (1) to quite a bit (3), with 80% sharing they feel their economic futures are uncertain, ranging from quite a bit (3) to very much

(4). All of the individuals reported fearing the adverse effects of treatment, ranging from a little bit (1) to very much (4), and 100% of individuals noted they fear their loved one will pass away, with scores ranging form somewhat (2) to very much (4). One hundred percent of caregivers reported feeling distressed seeing their loved one deteriorate, with 80% of individuals rating this as very true (4).

Nine staff members, including the program director and support group facilitators, completed the six-question survey. Four major themes emerged after completing the thematic analysis, including lack of self-care, increased fatigue, need for coping skills to address anticipatory grief, and increased anxiety and stress. Staff were asked what concerns or issues related to caregiving they have observed and could see as beneficial to include in a program to address caregiver's needs. Approximately 67% of staff members mentioned lack of self-care and approximately 44% mentioned the need for stress and anxiety management as important. Approximately 33% reported increased fatigue as a key factor and approximately 22% noted the need for pre-grieving, or anticipatory grieving, in case of potential loss. These four themes align with the five themes generated from the CQOL-C and ZBI, as anticipatory grief encompasses the fear associated with treatment and death. In addition, 40% of the caregivers interviewed made additional comments highlighting the importance of self-care for caregivers.

Comparison to Inpatient Setting

The responsibilities and burden associated with caring for survivors varies depending on the survivor's phase of cancer treatment (Given, Given, & Sherwood, 2012). This variation extends to the settings associated with each phase of treatment, "with a variety of needs that occur not only during the time of diagnosis and treatment but years after" (Kim, Kashy, Spillers, & Evans, 2010, pg. 581). The needs of survivors are not adequately being met in settings other than acute care (Polo et al., 2018), let alone the needs of caregivers. Romito and colleagues (2013) note that similar to caregivers of cardiac or stroke patients, training and resources for caregivers of cancer survivors should be included in the survivor's discharge plans. Findings suggest, although responsibilities of caregivers vary with each stage of cancer treatment (Given, Given, & Sherwood, 2012), studies examining caregiver's needs have determined "informational and psychological needs" as the most freqeuntly reported concerns amongst caregivers, regardless of setting (Grimm, Zawacki, Mock, Krumm, & Frink, 2000, p. 121). Given this information, a needs assessment completed in the inpatient setting would look similar to a needs assessment completed the community setting because caregiver's needs are not adequately being met in any OT setting. However, implementing a program for caregivers is most appropriate in the community setting because caregivers can better attend to their own needs as the survivor's health stabilizes.

Program Implementation

Three main interventions were completed during this doctoral capstone experience. The primary intervention, implemented by the occupational therapy student, was a one time, discussion-based, educational class for caregivers of cancer survivors at CSC. "Caring for those who Care" was held on March 12th, 2019 and lasted approximately two hours. "Caring for those who Care" was advertised in CSC's monthly calendar, *The Companion*, and announced at various programs and support groups held at CSC throughout the month prior to the class. After review of the completed needs assessments, four discussion topics were chosen for the session, including self-care, stress management, fatigue management, and anticipatory grief.

To begin the session, participants completed a brief introductory activity of sharing one self-care activity completed during the week prior in order to build participant rapport and transition into the first topic. Each topic consisted of an educational portion, including definitions, factual evidence, and strategies and skills developed from needs assessment findings and evidence based research.

Following the education portion, participants engaged in discussion based on three to four questions, developed from class content and evidence based literature findings per topic. The discussion portion concluded with the occupational therapy student encouraging participants to write down one or two strategies to implement in the coming weeks.

Before and after the session, participants completed a six-question pre and post survey, developed utilizing class content, evidence-based literature, and needs assessment results, which can be found in Appendix F. These surveys served as formative assessments, by measuring knowledge gained by each participant during the session. In addition to these surveys, each participant completed the CQOL-C and ZBI, which served as summative assessments to assess caregiver burden and quality of life. Two weeks after the class, a one-on-one consultation was completed with each participant, which consisted of reassessing their ZBI and CQOL-C scores after implementation of strategies and skills learned, as well as discussion on additional concerns.

The second intervention associated with the "Caring for those who Care" class consisted of the creation and distribution of an infographic, found in Appendix G. The infographic was created using class content, evidence-based literature, and utilized suggestions from the marketing director of CSC. The graphic contained the four discussion topics of self-care, stress management, fatigue management, and anticipatory grief, with key points bulleted underneath. In addition, CSC's contact information and a link to the third and final intervention, described below, were included. With permission from staff, the infographic was displayed at CSC's central location and distributed to CSC's networking sites, including Franciscan Health Cancer Center, Eskenazi Health, Community Health Network, and Hendricks Regional Health.

As mentioned above, the third and final intervention associated with this doctoral capstone was an online tool created for caregivers with community resources to facilitate caring for their loved ones. This tool was developed utilizing Google sheets, suggestions from CSC staff, and the magazine *Cancer Guide*. The tool is organized into separate pages by the various needs of cancer survivors and their caregivers, including but not limited to, basic living expenses, equipment/supplies expenses, childcare expenses, and medical care assistance. The contents of each page includes organization's titles, contact information with links to their websites, and mission statements. The goal for this tool is for it to be displayed on CSC's website to provide easier access to community resources for cancer survivors and their caregivers.

Leadership and Implementation

Leadership relies on effectiveness, emphasizing the skills of planning and communicating effectively, networking/ building relationships, and challenging, motivating, and inspiring others (Snodgrass, 2011). These effective leadership skills were essential for the implementation of "Caring for those who Care," as well as the creation and distribution of the infographic and online tool.

Prior to presenting the "Caring for those who Care" class, planning effectively was required to ensure all topics were covered thoroughly and concisely. Frequently inquiring if participants had questions throughout the implementation of the class and summarizing key points after each topic ensured effective communication throughout the session. Effective communication, specifically considering the components of health literacy and ease of use, were also key components in designing both the infographic and online tool. Networking and building relationships with CSC staff and participants was critical in the recruitment of participants for the class, distribution of the infographic, and the gathering of information for the creation of the online caregiver tool. Networking and building relationships required multiple months of rapport building and attending functions held by CSC. Challenging and motivating caregivers to attend the class and to implement one to two strategies from each topic was intended to inspire these individuals to complete self-compassionate care, putting their needs first.

Finally, initiation, communication, and self-directed learning have facilitated leadership growth throughout this doctoral experience. Initiating communication with staff and participants and taking initiative to attend programs, groups, and events fueled ideas for "Caring for those who Care's" program design and implementation, as well as the need for an online caregiver tool. Due to the nature of the community setting and the multitude of responsibilities of the occupational therapy student's site mentor, it was particularly important to be self-directed and take initiative during both the program development and implementation phases.

Staff Development and Implementation

Staff development was encouraged throughout the implementation phase. During initial meetings with the occupational therapy student's site mentor and program facilitator, OT's scope of practice was defined and applied to the community setting. The role of occupational therapy with survivors and their caregivers within the community setting continued to be highlighted and clarified throughout the implementation phase and during bimonthly meetings with CSC full-time staff, including program facilitators, interns, and participants. During the "Caring for those who Care" session, two interns from other health professions were educated on the course content, specifically the role of occupational therapy within the population of caregivers of survivors. Finally, staff development was encouraged while visiting CSC networking sites including Community Health Network, Eskenazi Health, and Franciscan Health. When the potential role of OT in survivorship care was described, one-on-one consultation appointments were marketed for patients to receive OT consultations through CSC.

Program Outcomes

Formative and summative assessments were utilized to measure knowledge gained and changes in quality of life and burden for each participant. Results of the formative, six-question and 12 point, pre and post surveys demonstrated an increase in knowledge gained of the "Caring for those who Care" session. This was evidenced by an average of a four-point improvement, from pre to post survey scores, across a total of five participants. Three caregivers and two CSC interns attended the session. It is important to note the range of improvement among scores was from three to five points, with 100% of participants gaining knowledge. On average, participants demonstrated the most significant improvement in knowledge of tips to improve self-care and energy conservation strategies.

Participants' summative, or CQOL-C and ZBI, scores were reassessed two weeks following the "Caring for those who Care" session to allow adequate time for strategy and skill implementation. Results varied due to two participants experiencing a significant decline in their survivor's health the week before the reassessment was completed. Despite total numerical scores indicating an increase in burden and decrease in quality of life for two, or 67%, of caregivers, upon further analysis of the scores, 100% of caregivers reported improvements in maintaining outside interests, decreased stress/worry, decreased mental strain, less fear about adverse effects of treatment on their loved one, improved sleep quality, increase in time spent on self-care activities, and improved outlook toward the future. This is evidenced by improved

CQOL-C scores on questions 2, 5, 10, 11, 15, as well as ZBI scores on questions 1, 2, and 5. These results can be viewed in more detail in Appendix H, Figures 1H and 2H. The caregiver whose scores indicated increased quality of life and decreased burden showed an improvement of 16 points, out of 140 total points on the CQOL-C, and two points, out of 48 total points, on the ZBI. Her most notable areas of improvement included ability to spend time on her outside interests, decreased mental strain, and a more positive outlook for the future. The participant shared, “I did not realize the importance of making time for myself and how much I was not doing that until the caregiver session.” Although, as previously mentioned, two participant’s results varied, both individuals reported the session was “extremely helpful” and inquired about CSC holding the session again, as well as additional caregiver support groups.

Quality Improvement

Quality improvement is critical for organizations to ensure client centered, quality care for individuals utilizing their services (LoBiondo-Wood, Haber, & Titler, 2018). The first steps to initiate quality improvement of a program are assessment and analysis, completed to better understand current performance and guide changes (LoBiondo-Wood, Haber, & Titler, 2018). Successful methods of gathering this information are conducting surveys and interviews (LoBiondo-Wood, Haber, & Titler, 2018).

Immediately following “Caring for those who Care” and two weeks following the session during reassessments of the CQOL-C and ZBI, participants were interviewed and asked to share elements of the session they enjoyed and elements they would improve upon. In the future, according to quality improvement results, CSC can improve this session by breaking up each topic into individual sessions to allow for more in-depth discussion and include strategies to cope with grieving when a loved one passes away suddenly.

Quality improvement, as it relates to the ongoing implementation of “Caring for those who Care” at CSC, will be ensured through the continued use of formative and summative assessments; the pre and post surveys, CQOL-C, and ZBI as objective measures will be used to guide program changes. In addition, the interview questions immediately following the session and two weeks after the session will continue to be utilized to provide subjective measures to guide program changes.

Meeting the Societal Need

The purpose of this doctoral experience was to meet the unmet needs of caregivers at CSC to ultimately improve their own quality of life and decrease the burden associated with caregiving. As previously mentioned, approximately 86% of 188 caregivers of individuals with a variety of cancer diagnoses reported their needs were unmet (Lapid et al., 2016; Sklenarova et al., 2015). As a result of these unmet needs, caregivers are experiencing caregiver burden and decreased quality of life (Almutairi et al., 2017; Tan et al., 2018).

In order to meet the needs of caregivers at CSC, the OT student implemented “Caring for those who Care,” tailored specifically to meet caregivers at CSC’s needs following the results of the needs assessment and evidence-based literature. This directly met the needs of caregivers by addressing their specified concerns in the areas of self-care, stress management, fatigue management, and anticipatory grief. Participants were not only provided with skills and strategies for each topic, but they were also contacted two weeks following the provision of these skills and strategies to address concerns and questions following implementation.

Although only 33% of caregivers who attended the session reported improved QoL and decreased caregiver burden, as evidenced by ZBI and CQOL-C scores, further analysis of the scores demonstrated an improvement for 100% of participants in topic areas addressed during the "Caring for those who Care" session. One participant even shared, "I've completely shifted my focus to my own self-care." In addition to the design and implementation of "Caring for those who Care," the OT student's goal for the creation and distribution of the infographic and online tool was to improve QoL and decrease burden beyond CSC to reach more caregivers in the Indianapolis community.

Sustainability

To ensure sustainability of "Caring for those who Care" to continue meeting the needs of caregivers in the greater Indianapolis area, the DCE student provided CSC with 2 protocol binders for the session. These binders contained the infographic, educational content, assessments, and a detailed protocol of the intended session format, goals, needed supplies, and the student's contact information for future inquiries. The contents of the protocol binders were also made available to the student's site mentor on Google Drive to more easily disseminate to facilitators of caregiver support groups. A support group facilitator at CSC has agreed to sustain the resources and programming to continue meeting the needs of caregivers in the greater Indianapolis area.

To ensure sustainability of the online tool, the DCE student utilized Google Sheets, granting access to the resource for anyone with the link and Internet access. The DCE student provided the site mentor with editing abilities to add and remove resources as needed.

Communication

Communication with CSC staff, participants, and mentors of the OT student was a key component of the success of this DCE project. Both written and oral communications were utilized to recruit participants for both the needs assessment and implementation stages. In addition, oral communication during staff meetings promoted advocacy for "Caring for those who Care" and the OT profession as whole, resulting in an increased understanding of OT's role with caregivers of survivors in the community setting. This was evidenced by referrals to "Caring for those who Care" from CSC staff and interns of other health professions. In addition, therapeutic use of self through non-verbal communication was crucial during the discussion portion of the session to demonstrate empathy and active listening. The OT student improved in both oral and written communications in the areas of professional terminology, health literacy, and conflict resolution throughout this doctoral experience. This was demonstrated by email communication with site and faculty mentors, use of terminology and formatting on the infographic, and clarification of the purpose of the DCE and OT's scope of practice with CSC interns. These improvements in communication skills ensured the successful completion of the OT student's three primary goals prior to beginning the capstone experience, including identifying OT's role in the community setting with the caregivers of survivors, implementing a health and wellness session, and developing an evidenced based caregiver resource.

Leadership and Advocacy

As previously mentioned, in addition to attending staff meetings to advocate for OT, the OT student educated CSC participants and interns from other health professions throughout the doctoral experience on OT's scope of practice. This included OT's role within the community setting and with the population of caregivers of cancer survivors. The OT student also had the opportunity to present to CSC's board of directors about "Caring for those who Care" and answer questions about OT's role in the community setting.

According to Braveman, leadership is "a process of change whereby we hope to impact others in some sustainable manner and have lasting impact on the function of a department or organization" (2016, p.6). Self-directed learning has been the primary factor in the OT student's leadership development. Self-directed learning influenced efficient and effective communication and planning, goal setting, as well as networking and building relationships to design and implement a sustainable session, “Caring for those who Care,” as well as the design and distribution of the infographic and online tool to create lasting resources for caregivers at CSC.

Conclusion

This DCE demonstrates that the “Caring for those who Care” session is a promising program for OTs who wish to educate caregivers of cancer survivors in the community setting. Community based educational programs such as “Caring for those who Care,” which offer strategies and skills for caregivers’ most commonly reported burdens, are a valuable contribution to the increasing population of caregivers of survivors. Research in this area will serve to gain further insight on this critical issue for caregivers.

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Appendix A

Caregiver Quality of Life Index- Cancer

Below is a list of statements that other people caring for loved ones with cancer have said are important. By circling one number per line, please indicate how true each statement has been for you *<u>during the past 7 days</u>.*

0 = Not at all
1 = A little bit
2 = Somewhat
3 = Quite a bit
4 = Very much

<u>During the past 7 days</u>:

1.	It bothers me that my daily routine is altered.	0	1	2	3	4
2.	My sleep is less restful.	0	1	2	3	4
3.	My daily life is imposed upon.	0	1	2	3	4
4.	I am satisfied with my sex life.	0	1	2	3	4
5.	It is a challenge to maintain my outside interests.	0	1	2	3	4
6.	I am under a financial strain.	0	1	2	3	4
7.	I am concerned about our insurance coverage.	0	1	2	3	4
8.	My economic future is uncertain.	0	1	2	3	4
9.	I fear my loved one will die.	0	1	2	3	4
10.	I have more of a positive outlook on life since my loved one's illness.	0	1	2	3	4
11.	My level of stress and worries has increased.	0	1	2	3	4
12.	My sense of spirituality has increased.	0	1	2	3	4
13.	It bothers me, limiting my focus to day-to-day.	0	1	2	3	4
14.	I feel sad.	0	1	2	3	4
15.	I feel under increased mental strain.	0	1	2	3	4
16.	I get support from my friends and neighbors.	0	1	2	3	4
17.	I feel guilty.	0	1	2	3	4
18.	I feel frustrated.	0	1	2	3	4

0 = Not at all **2** = Somewhat
1 = A little bit **3** = Quite a bit
4 = Very much

19. I feel nervous. 0 1 2 3 4

20. I worry about the impact my loved one's illness has had on my children or other family members. 0 1 2 3 4

21. I have difficulty dealing with my loved one's changing eating habits. 0 1 2 3 4

22. I have developed a closer relationship with my loved one. 0 1 2 3 4

23. I feel adequately informed about my loved one's illness. 0 1 2 3 4

24. It bothers me that I need to be available to chauffeur my loved one to appointments. 0 1 2 3 4

25. I fear the adverse effects of treatment on my loved one. 0 1 2 3 4

26. The responsibility I have for my loved one's care at home is overwhelming. 0 1 2 3 4

27. I am glad that my focus is on getting my loved one well. 0 1 2 3 4

28. Family communication has increased. 0 1 2 3 4

29. It bothers me that my priorities have changed. 0 1 2 3 4

30. The need to protect my loved one bothers me. 0 1 2 3 4

31. It upsets me to see my loved one deteriorate. 0 1 2 3 4

32. The need to manage my loved one's pain is overwhelming. 0 1 2 3 4

33. I am discouraged about the future. 0 1 2 3 4

34. I am satisfied with the support I get from my family. 0 1 2 3 4

35. It bothers me that other family members have not shown interest in taking care of my loved one. 0 1 2 3 4

Appendix B
Zarit Burden Interview

ZARIT BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

	Never	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
1) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
3) Do you feel angry when you are around the relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your relative?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel that 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 your 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

Appendix C

Caregiver Burden Program Needs Assessment

Aubriel Wooley, OTS (Occupational Therapy Intern)

The Cancer Support Community defines cancer caregivers as family members, spouses, partners and friends who take on a caregiving role and have a unique relationship to cancer (CSC, 2016).

1. When working with caregivers of individuals with cancer, have any of these individuals reported concerns or issues related to caregiving?
2. Similarly, when conversing with other staff members, have they recounted issues or concerns reported or observed by caregivers related to caregiving?
3. If you answered yes to question (1) or (2), what are some common themes or topics you have noted?
4. From these themes, which of these do you think would be beneficial to include in a program designed to improve the quality of life and overall wellness of caregivers of individuals with cancer?
5. Have any of the sites CSC networks with reported caregiver concerns different from those you have already mentioned? If so, what are they?
6. Do you have any additional suggestions for either the formation/delivery of the needs assessment or the creation of the program itself?

Appendix D
SWOT Analysis

Strengths	• Caregiver support group (Friends & Family) currently available • Caregivers encouraged to attend programs with survivors • CSC has many network connections to engage caregivers and promote programs and support groups • Ample space and supplies to host programs/groups • CSC is respected throughout community and has a good reputation
Weaknesses	• Lack of programs designed specifically to meet caregivers' needs • Minimal caregiver attendance at groups and programs • Minimal resources/handouts specifically for caregivers
Opportunities	• Improve caregivers' quality of life through tailored programs • Meet caregivers' unmet needs with one on one consultations • Educate staff on caregivers' reported needs • Provide outline/guide for staff to continue program
Threats	• Geographical location –many programs/groups only held at West Indianapolis location • Continuation of program after DCE concludes

Appendix E
Caregiver Needs Assessment Results

Topic	% of Caregivers Reported	Ranges of Intensity
Stress/Worry associated with Caregiving	80%	Quite a Bit (3) – Very Much (4)
Increased Mental Strain	100%	Somewhat (2) – Very Much (4)
Less Restful Sleep	100%	Somewhat (2) – Very Much (4)
Financial Strain	100%	A Little Bit (1) – Quite a Bit (3)
Uncertainty about Economic Future	80%	Quite a Bit (3) – Very Much (4)
Fear Adverse Effects of Treatment on Loved One	100%	A Little Bit (1) – Very Much (4)
Fear Loved One will Pass Away	100%	Somewhat (2) – Very Much (4)
Distress Seeing Loved one Deteriorate	100%	Quite a Bit (3) – Very Much (4)

Appendix F
Pre/Post Survey Questions

1. True or False: Fatigue encompasses both physical and mental components.
2. True or False: Men and women typically experience anticipatory grief similarly.
3. True or False: Anticipatory grief can help reduce the complexity of grief after losing a loved one.
4. True or False: When provided with stress management tips, caregivers no longer neglect their own self-care.
5. What are 3 tips for improving your self-care?

   (1)

   (2)

   (3)

6. The 5 main strategies for conserving energy during everyday tasks include:

   (1)

   (2)

   (3)

   (4)

   (5)

Appendix G
Infographic

CARING FOR THOSE WHO CARE

Created By: Aubriel Wooley

Self-Care

- Personal Awareness
- Social Support Groups
- Relaxation Techniques
- Exercise
- Improve Sleep Quality
- Nutrition

Stress Management

- Yoga, Tai-Chi, & Meditation
- Pleasant Imagery
- Progressive Muscle Relaxation
- Journaling

Fatigue Management

- Prioritize Activities
- Plan Ahead
- Delegate/Discard Tasks
- Pacing/Time Management
- Modify Tasks

Anticipatory Grief

- Losses are ongoing
- Different & more concentrated than post-death grief
- Manifests physically, emotionally, & cognitively

CONTACT INFO:
317-257-1505
5150 W 71st St,
Indianapolis, IN 46268

CANCER SUPPORT COMMUNITY
So that No One Faces Cancer Alone

For community resources for caregivers of cancer survivors, please visit this link:

https://docs.google.com/spreadsheets/d/1_3LhJY_VVmW3QYtGHl4HH5AnBV40k6SaFFnTdBWxDxY/edit?usp=sharing

Appendix H
Results of Pre & Post Session Scores

Table 1H

Zarit Burden Interview Results

Do you feel…	Session Scores	Never (0)	Rarely (1)	Sometimes (2)	Quite Frequently (3)	Nearly Always (4)
(1) because of time spent with relative you don’t have enough time for yourself?	Pre	--	--	33%	67%	--
	Post	--	33%	67%	--	--
(2) stressed between caring for relative and meeting other responsibilities?	Pre	33%	--	33%	33%	--
	Post	--	67%	33%	--	--
(3) angry when you are around your relative?	Pre	67%	33%	--	--	--
	Post	33%	67%	--	--	--
(4) your relative affects your relationships with other family members negatively?	Pre	33%	--	67%	--	--
	Post	33%	--	33%	--	33%
(5) strained when you are around your relative?	Pre	33%	--	67%	--	--
	Post	33%	67%	--	--	--
(6) your health has suffered because of your involvement with your relative?	Pre	--	--	67%	33%	--
	Post	--	--	67%	33%	--
(7) you don’t have as much privacy as you would like because of your relative?	Pre	--	--	100%	--	--
	Post	33%	33%	33%	--	--
(8) your social life has suffered because you are caring for your relative?	Pre	--	33%	33%	--	33%
	Post	--	--	33%	67%	--
(9) you have lost control of your life since your relative’s illness?	Pre	--	--	33%	67%	--
	Post	--	--	33%	67%	--
(10) uncertain about what to do about your relative?	Pre	33%	--	33%	33%	--
	Post	--	--	67%	33%	--

(11) you should be doing more for your relative?	Pre	33%	--	67%	--	--
	Post	33%	33%	33%	--	--
(12) you could be doing a better job in caring for your relative?	Pre	33%	--	67%	--	--
	Post	33%	33%	33%	--	--

Table 2H

CQOL-C Results

	Session Scores	Not at all (0)	A little bit (1)	Somewhat (2)	Quite a bit (3)	Very Much (4)
(1) It bothers me that my daily routine is altered	Pre	--	33%	67%	--	--
	Post	33%	--	33%	33%	--
(2) My sleep is less restful	Pre	33%	33%	--	33%	--
	Post	67%	33%	--	--	--
(3) My daily life is imposed upon	Pre	--	100%	--	--	--
	Post	--	67%	--	--	33%
(4) I am satisfied with my sex life	Pre	--	33%	67%	--	--
	Post	--	67%	--	--	33%
(5) It is a challenge to maintain my outside interests	Pre	--	33%	--	--	67%
	Post	--	33%	67%	--	--
(6) I am under a financial strain	Pre	33%	--	67%	--	--
	Post	33%	33%	33%	--	--
(7) I am concerned about our insurance coverage	Pre	33%	67%	--	--	--
	Post	67%	--	33%	--	--
(8) My economic future is uncertain	Pre	67%	33%	--	--	--
	Post	67%	--	--	33%	--
(9) I fear my loved one will die	Pre	33%	--	--	--	67%
	Post	--	33%	--	--	67%
(10) I have more of a positive outlook on life since my loved one's illness	Pre	--	--	100%	--	--
	Post	33%	67%	--	--	--
(11) My level of stress and worries has increased	Pre	--	--	--	33%	67%
	Post	--	--	33%	67%	--

	Not at all (0)	A little bit (1)	Somewhat (2)	Quite a bit (3)	Very Much (4)	Session Scores
(12) My sense of spiritualty has increased	Pre	33%	--	67%	--	--
	Post	--	33%	67%	--	--
(13) It bothers me, limiting my focus to day-to-day	Pre	--	33%	33%	33%	--
	Post	--	33%	67%	--	--
(14) I feel sad	Pre	--	--	67%	33%	--
	Post	--	33%	--	--	67%
(15) I feel under increased mental strain	Pre	--	--	67%	33%	--
	Post	--	67%	33%	--	--
(16) I get support from my friends and neighbors	Pre	--	67%	33%	--	--
	Post	--	67%	33%	--	--
(17) I feel guilty	Pre	100%	--	--	--	--
	Post	100%	--	--	--	--
(18) I feel frustrated	Pre	--	33%	--	67%	--
	Post	--	33%	--	33%	33%
(19) I feel nervous	Pre	33%	33%	--	33%	--
	Post	67%	--	33%	--	--
(20) I worry about the impact my loved one's illness has had on my children or other family members	Pre	--	33%	--	67%	--
	Post	--	--	--	67%	33%
(21) I have difficulty dealing with my loved one's changing eating habits	Pre	--	--	--	33%	67%
	Post	--	--	--	33%	67%
(22) I have developed a closer relationship with my loved one	Pre	--	33%	33%	33%	--
	Post	33%	--	33%	33%	--
(23) I feel adequately informed about my loved one's illness	Pre	--	--	--	67%	33%
	Post	--	--	--	67%	33%

	Not at all (0)	A little bit (1)	Somewhat (2)	Quite a bit (3)	Very Much (4)	Session Scores
(24) It bothers me that I need to be available to chauffeur my loved one to appointments	Pre	33%	67%	--	--	--
	Post	33%	33%	--	--	33%
(25) I fear the adverse effects of treatment on my loved one	Pre	--	33%	--	33%	33%
	Post	--	67%	33%	--	--
(26) The responsibility I have for my loved one's care at home is overwhelming	Pre	--	33%	67%	--	--
	Post	--	33%	33%	--	33%
(27) I am glad that my focus is on getting my loved one well	Pre	--	33%	33%	--	33%
	Post	--	--	--	100%	--
(28) Family communication has increased	Pre	--	33%	67%	--	--
	Post	--	33%	33%	33%	--
(29) It bothers me that my priorities have changed	Pre	--	33%	33%	33%	--
	Post	--	33%	33%	33%	--
(30) The need to protect my loved one bothers me	Pre	--	33%	--	67%	--
	Post	--	--	33%	33%	33%
(31) It upsets me to see my loved on deteriorate	Pre	--	--	--	33%	67%
	Post	--	--	--	--	100%
(32) The need to manage my loved one's pain is overwhelming	Pre	--	--	--	33%	67%
	Post	--	33%	--	33%	33%
(33) I am discouraged about the future	Pre	--	33%	33%	--	33%
	Post	33%	67%	--	--	--
(34) I am satisfied with the support I get from my family	Pre	--	--	33%	33%	33%
	Post	33%	--	--	67%	--
(35) It bothers me that other family members have not shown interest in taking care of my loved one	Pre	--	--	--	33%	67%
	Post	--	--	--	67%	33%