UNMET NEEDS OF INFORMAL CANCER CAREGIVERS: A MIXED-METHODS APPROACH TO IDENTIFY NEEDS

By

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This is to certify that Jamie Kerner

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Abstract

Problem under investigation: Many cancer caregivers often have a number of unmet needs that leads to distress, burden, and poor patient outcomes.

Objective: Identify unmet needs of informal cancer caregivers at Roswell Park, provide a compendium of local community resources, and recommend additional resources that other cancer centers in the nation utilize.

Background literature and theoretical framework: In the United States there are more than 14.5 million cancer survivors. Cancer caregivers lack the knowledge, support, and self-confidence to properly care for their loved ones. The theory of Caregiver Stress states that inputs, which are defined as internal and external factors, are associated with unmet needs and burden. Inputs have a direct impact on outcomes.

Project methods: Mixed-methods approach to data collection using the Caregiver Self-Assessment Questionnaire and focus groups. Email interviews were conducted with oncology experts at cancer centers around the nation.

Results: Informal caregivers at Roswell Park expressed feelings of unmet needs and caregiver burden. Oncology experts at various cancer centers in the nation are concerned that caregivers at their institutes are not properly managed; however, a significant number of online and local resources for caregivers were identified but are likely not being utilized to the full potential.

Potential significance: Enhance the caregiver role through knowledge of resources to minimize unmet needs and burden.

Implications: Informing caregivers and healthcare providers of the resources available to them will help minimize unmet needs and lessen the degree of burden that will improve outcomes.

Keywords: Cancer, Caregiver, Burden, Needs, Unmet Needs
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Introduction

Currently in the United States alone there are more than 14.5 million cancer survivors, this number continues to grow as treatments are evolving and patients are living longer (Kent et al., 2016). According to the American Cancer Society the number of survivors is estimated to increase to an astounding 20.3 million by the year 2026 (American Cancer Society, 2016). The needs of cancer caregivers are frequently overlooked even though evidence suggests that the health outcomes of patients and caregivers are often related (Kent et al., 2016). Caregiver burden is a pertinent problem within the health care field and can occur at any time. Physicians, advanced practice providers (APPs), nurses, social workers, psychologists, and discharge planners have a pivotal role in decreasing caregiver burden. Informal caregivers (ICGs) are defined as those who provide a significant amount of care for an individual for months or years. ICGs are typically unpaid and will often experience emotional, social, physical, and financial demands related to caregiving (Kent et al., 2016).

Caregiver burden can be defined as a somatic or emotional response to the numerous stressors unloaded on caregivers. Stressors include lack of personal time, role conflict, physical and emotional wellbeing, financial stress, and lack of caregiver support (Bialon & Coke, 2012). ICGs provide up to 90% of outpatient care required by adult patients (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). ICGs spend the majority of their time with the patient, and the health outcomes of both caregivers and patients are directly related, and as a result of these reasons, there needs to be a stronger focus on caregivers of chronically ill patients. A goal of advanced practice nurses, as well as other members of the interdisciplinary healthcare team, is to minimize risk and improve health outcomes.
UNMET NEEDS

**Background and Significance**

A study conducted by Sharpe et al. found that, when questioned about the needs of patients, patients and healthcare providers underestimated unmet patient needs and the available support when compared to the caregiver (2005). Evidence has shown that ICGs often feel lost within the healthcare system and do not feel they receive adequate support (Adelman et al., 2014). Risk factors for developing caregiver burden include: financial stress, social isolation, and hours spent providing care (Adelman et al., 2014). ICGs of chronically ill patients who require frequent medical care are at a high risk of developing caregiver burden. Burden has been shown within the literature to impact patient outcomes negatively (Adelman et al., 2014). The needs of ICGs are often overlooked by health care professionals (Kent et al., 2016). Unfortunately, the majority of ICGs report feeling burdened with numerous unmet needs, feel underprepared and unacknowledged (Kent et al., 2016). Due to their unmet needs and minimal social support, ICGs cannot effectively care for their loved ones resulting in poor health outcomes for both ICGs and caregivers (Chen et al., 2016). As reported by Bialon and Coke, the longer an ICG provides assistance to someone the lower their reported quality of life (2012).

Unmet caregiver needs and burden is not a problem associated with only those who care for cancer patients. Unmet needs are a problem that spans across the entire ICG population, especially with individuals caring for patients with chronic illnesses. Interdisciplinary team members must be informed of the current scope of the problem. Interdisciplinary team members must work as a cohesive unit to provide patients and their ICGs with the proper resources they need. The literature review focuses mostly on caring for cancer patients but also describes caregiving for those with another chronic illness, to highlight the true scope of the problem.
Purpose

The purpose of this Doctor of Nursing Practice (DNP) project is to identify unmet needs of ICGs of cancer patients at Roswell Park Comprehensive Cancer Center (RPCCC) and to make recommendations for caregiver resources. Resources recommendations are based upon identified unmet needs and data collected from other cancer centers around the nation. These resources will potentially enhance quality of life, health, and minimize caregiver burden. This DNP project would benefit a wide range of healthcare professionals including advanced practice providers (APPs), physicians, social workers, nurses, and discharge planners. A key objective is to provide healthcare professionals with resources they need to reduce the degree of caregiver burden. Based on the needs identified, a compendium of local community resources was developed to enhance access to care and support. This project highlights the importance of interdisciplinary collaboration and coincides with the DNP essential VI as described by the American Association of Colleges of Nursing (AANC). Essential VI, *Interprofessional Collaboration for Improving Patient and Population Health Outcomes* describes the importance of individuals from different professions working together to improve care and outcomes. addresses the importance of interdisciplinary collaboration to improve outcomes (AANC, 2006). Doctorally prepared advanced practice nurses have the knowledge, responsibility and skill to develop a cohesive interdisciplinary team (AANC, 2006). This DNP project attempts to answer the question, what are the unmet needs of ICGs at RPCCC, and what resources could be implemented to improve patient and caregiver outcomes to decrease burden?

Literature Review

The role of an informal caregiver in the United States has expanded as the population continues to age (Bialon & Coke, 2012). Caregiver burden is described as an emotional and
physical response to the imbalance of demands (Bialon & Coke, 2012). Emotional and social supports are two factors that have a significant impact on the degree of burden of ICGs (Bialon & Coke, 2012). ICGs with limited emotional and social support suffered from increased depressive symptoms and reported lower life satisfaction respectively (Bialon & Coke, 2012). Interventions targeted to address unmet needs of ICGs showed positive results in decreasing burden symptoms, such as spiritual care, improved caregiver knowledge, and emotional support (Bialon & Coke, 2012). Bialon and Coke conducted interviews with nine ICGs and found four major themes regarding their experiences with caregiving (2012). The identified themes were decline in caregiver health, role conflict, lack of physical and emotional support, and faith (Bialon & Coke, 2012). Decline in caregiver health is an umbrella term used to describe how a caregiver perceives their emotional and physical well-being. Bialon and Coke’s study described changes in sleep patterns, changes in weight, and emotional turmoil to be a subset of decline in caregiver health (2012). Role conflict is defined as the struggle to balance personal and patient needs and was discovered as a common problem among the majority of caregivers (Bialon & Coke, 2012). Caregivers expressed their frustration with the lack of physical and emotional support their families provided (Bialon & Coke, 2012). Faith was described as an alleviating factor to the burden of caregiving (Bialon & Coke, 2012). Caregivers stated how faith augmented their capacity to manage the many challenges of caregiving and even the grieving process after death (Bialon & Coke, 2012).

Premkumar, Arun, Tharyan, and Inbakamal (2018) used a cross-sectional study method to identify different variables that increased the amount of caregiver burden. The degree of patient disability contributed most to increased caregiver burden (Premkumar et al., 2018). Patients who needed help completing activities of daily living (ADLs) had caregivers with an
increased level of burden versus caregivers of patients who were independent with ADLs (Premkumar et al., 2018). The article also found that neither age nor gender of the caregiver or patient significantly impacted the degree of burden.

Primary caregivers are most often the patient’s spouse or partner (Figved, Myhr, Larsen, & Aarsland, 2007). Partners must deal with the stress related to a diagnosis of a chronic illness, which will impact their own lives (Figved et al., 2007). This realization can have a significant impact on the psychological health of a caregiver, which is why interventions are necessary to help these individuals to continue caregiving but also to “[maintain] themselves in the process” (Figved et al., 2007, p. 1097). Figved et al. divided caregivers into four groups: spouses, adult children, parents, and friends (2007). Figved et al. concluded that spouses had a higher degree of burden and lower quality of life than any other caregiver group. Friends were found to have the lowest degree of burden and highest quality of life when compared to any other caregiver group (2007).

Rodakowski, Skidmore, Rogers and Schulz (2012) focused their research on the role of social support in caregiver burden. The authors used a cross-sectional study method to examine burden of caregivers of aging adults with spinal cord injury (SCI). The article found that higher degree of burden was associated with a higher incidence of morbidity and mortality as well as poor life-satisfaction (Rodakowski et al., 2012). Another significant finding was that degree of burden and social isolation are directly related; those with a higher degree of burden usually experience social isolation (Rodakowski et al., 2012). The authors concluded that in home services as well as caregiver social support appear to have the largest impact on the reduction of burden (Rodakowski et al., 2012).
When focusing on ICGs of Multiple Sclerosis (MS) patients, Buchanan, Radin, and Huang (2011) found that 80% of supportive care at home was provided by ICGs, which was most commonly the patient’s spouse. Increasing severity of MS symptoms correlated with increased caregiver burden. Greater than 20% of ICGs admitted that caring for their loved one with MS was burdensome (Buchanan, Radin, & Huang, 2011). ICGs of MS patients were invited to participate in a study where they would answer interview questions related to caregiving. Burden was then measured using a 5-point Likert scale. Results of the study showed that the amount of time providing care was directly associated with level of burden (Buchanan, Radin, & Huang, 2011). About half of the study participants admitted to providing 20 hours or more of care per week to their loved one (Buchanan, Radin, & Huang, 2011). Respite care, such as adult day care, and in home respite services, were found to greatly impact caregiver burden (Buchanan, Radin, & Huang, 2011). Unfortunately, more than 30% of caregivers needed respite care but neglected asking for such services (Buchanan, Radin, & Huang, 2011). This statistic highlights the need to improve caregiver education by the APPs. Additionally, about 25% of ICGs of MS patients reported the need to seek mental health services, but less than one third of ICGs sought out professional help (Buchanan, Radin, & Huang, 2011). Buchanan, Radin, and Huang concluded that future research should focus on programs and resources intended to reduce burden (2011).

As described in a study by Mausbach et al., providing care is associated with high levels of stress, increased risk of cardiovascular disease (CVD), and increased mortality (2017). The authors suggest that the elevated risk of CVD is related to elevated blood pressure as a result of increased levels of stress (Mausbach et al., 2017). Caregiving for an Alzheimer’s patient is associated with a 67% increased risk of developing hypertension when compared to non-
caregiver counterparts (Mausbach et al., 2017). “Hypertension is the strongest and most robust risk factor for CVD” (Mausbach et al., 2017, p. 735). The authors conducted a study on informal spousal caregivers of Alzheimer’s patients where they examined the relationship between participating in pleasure activities and blood pressure over time (Mausbach et al., 2017). The results of the study showed that participating in pleasure activities more frequently was associated with a significant decrease in mean arterial pressure and diastolic pressure (Mausbach et al., 2017).

In 2015, Sklenarova et al. performed a cross-sectional survey asking ICGs of cancer patients to fill out a self-reported survey on supportive care needs. The purpose of the study was to assess the unmet needs of ICGs of patients diagnosed with cancer. The study revealed that more than 14% of ICGs had unmet needs, and 43.6% of ICGs had at least 10 unmet needs (Sklenarova et al., 2015). The unmet needs of cancer ICGs were in the category of health care, information, emotional, and psychological needs (Sklenarova et al., 2015). The authors identified the top ten unmet needs from most reported to least reported. The top five unmet needs were fear regarding patient deterioration, concerns of cancer recurrence, feelings towards death, information about alternative therapies, and confidence in coordinated care (Sklenarova et al., 2015). The next five unmet needs were identified as obtaining the best medical care, having an ongoing case manager to coordinate services, access to information about side effects and benefits of treatments, decision making, and accessibility to information on prognosis and outcomes (Sklenarova et al., 2015). Another study by Chen et al. in 2016, reported that roughly 44% of ICGs of cancer patients reported to have a minimum of ten unmet needs.

In 2016 Kent et al. stated that many cancer ICGs lack the knowledge, support or self-confidence to properly care for their loved ones. One of the recommendations presented by the
authors is to expand healthcare from patient to family centered in hopes of decreasing the unmet needs of cancer caregivers (Kent et al., 2016).

Patients continue to live longer than in previous years, and care is shifting to earlier discharges and utilization of outpatient management. Because of these changes, caregivers now have an increase in responsibility (Sharpe et al., 2005). Cancer ICGs have been found to have higher incidences of mental health illnesses than their non-caregiving counterparts (Sharpe et al., 2005). When compared to patients and healthcare professionals, ICGs generally reported a higher amount of unmet needs and a lower amount of available support (Sharpe et al., 2005). Over time, as the patient’s health condition declines, the amount of support and resources for the caregiver remained the same as opposed to increasing with the increased needs (Sharpe, 2005).

Worldwide, lung cancer is the leading cause of death (Chen et al., 2016). Chen et al. describes that patients experience significant amount of distress related to their lung cancer diagnosis and treatment modalities, which generally include chemotherapy and radiation treatments (2016). ICGs of these patients’ experienced significant health and work impairments along with financial burdens, which emphasized the need to improve ICG support (Chen et al., 2016).

Caring for cancer patients can be a stressful experience for ICGs. Caring for terminally ill cancer patients at the end of life (EOL) can pose additional stress and emotional turmoil. “Caregivers of terminal cancer patients face extraordinary stresses owing to the patients’ multiple symptoms and their own psychological suffering…Because caregivers form a substantial part of the healthcare system, we need to better understand their burden and its impact on the quality of terminal care they provide” (Park, Kim, Kim, Choi, Lim, & Choi, 2010, p. 699). The authors of the study found that roughly 25% of ICGs admitted to needing psychosocial
support and about 21% of those individuals reported that this need had not been met (Park et al., 2010). Around 32% of ICGs reported a need for community support and around 20% of those individuals stated that this need was unmet (Park, et al., 2010). The results of the study show that ICGs are aware that they need support, but the majority are not receiving the support they need (Park et al., 2010).

Bone Marrow Transplant (BMT) ICGs often have unmet needs leading to fatigue, problems sleeping, depressive symptoms, and sexual dysfunction (Armoogum, Richardson, & Armes, 2013). The purpose of the study conducted by Armoogum, Richardson, and Armes was to identify unmet needs using a cross-sectional survey of BMT ICGs within two years of transplant (Armoogum, Richardson, & Armes, 2013). The participants of the study used the Supportive Care Needs Survey to indicate their level of need for help for each item (Armoogum, Richardson, & Armes, 2013). Items with a score of four or five are considered to be a moderate or high-level need (Armoogum, Richardson, & Armes, 2013). Of the study participants, almost half were found to experience psychological morbidity. Also, 66% of participants had at least one moderate or high level unmet need and 32% experienced multiple unmet needs (Armoogum, Richardson, & Armes, 2013). Some of the top unmet needs discovered by Armoogum, Richardson, and Armes were receiving emotional support, balancing patient needs with personal needs, financial support, and looking after the ICGs own health (2013). The authors of this study recommended that further research should involve qualitative data collection to identify unmet caregiver needs and discover resources that would be deemed beneficial (Armoogum, Richardson, & Armes, 2013).
Conceptual Framework

Roy’s Adaptation Model

Roy’s Adaptation Model (RAM) was originally created in 1970 and has been revised several times with the most recent revision in 1991 (Tsai, 2003). The final revision brought about a more holistic and interactive approach to understand how individuals interact and cope with their environment (Tsai, 2003). RAM states that if the combined life stimuli are less than that of an individual’s adaptation level, then the individual will be able to adapt to different situations (Tsai, 2003). However, if the combined effects of life stimuli are greater than an individual’s adaptation level, the individual will not be able to appropriately cope with situations (Tsai, 2003). According to RAM, coping mechanisms are either learned through environment or are innate (Tsai, 203). Stimuli experienced throughout the life-time, such as the stressors of caregiving, can impact an individual’s ability to cope (Tsai, 2003).

Theory of Caregiver Stress

The Theory of Caregiver Stress was developed in 1984 as a derivative of RAM (Tsai, 2003). The theory describes a series of inputs that are focal, contextual, and residual (Tsai, 2003). Focal inputs are related to responsibilities associated with caregiving that include, but are not limited to, time spent caregiving or the financial impact it has on the family (Tsai, 2003). Contextual inputs are stressful life events unrelated to patient caregiving such as change in family residence or a death in the family. Finally, residual inputs are associated with ICG demographics such as age and gender (Tsai, 2003). The theory also mentions outputs that are associated with the caregiver stress and are described as physical malfunctioning that can be identified as poor caregiver health (Tsai, 2003). Also, self-esteem and mastery are also considered to be an output of the theory. Self-esteem is associated with perceived self-worth, and
typically ICGs have lower self-esteem due to feelings of inadequacy. Mastery is associated with the ICG perception of control (Tsai, 2003). Appendix A depicts the basic structure of the Theory of Caregiver Stress with regards to inputs, how the inputs impact the ICG, and the associated outcomes. The combination of inputs leads to the ICGs perceived degree of burden. The higher perceived burden leads to higher levels of depression (Tsai, 2003). As anticipated, high levels of burden and depression promotes poorer outputs or outcomes (Tsai, 2003).

**Methodology**

**Design**

The DNP project was a mixed-methods design utilizing descriptive statistics and thematic analysis. Descriptive statistics was used to analyze the quantitative data that was collected through the Caregiver Self-Assessment Questionnaire. The information collected via the questionnaire was used to identify which ICGs were experiencing high levels of distress. The qualitative data was extracted through thematic analysis of focus group discussions. At the conclusion of the focus groups, the recorded discussion was then transcribed. The transcription was analyzed to identify themes within the discussion.

How qualitative data is interpreted plays a role in the results of the study. There are many different phases of interpreting qualitative data (Crabtree & Miller, 1999). The first phase is the describing phase, which is when a researcher takes the time to reflect upon the data and how the data is affecting the interpretative process (Crabtree & Miller, 1999). The second phase is the organization of the data. Data should be organized by how it answers the research question (Crabtree & Miller, 1999). The third phase is the connecting phase, which is when the researcher identifies themes or patterns within the data (Crabtree & Miller, 1999). The fourth phase is the concern with the credibility of data interpretations (Crabtree & Miller, 1999). To assist with this
step of the qualitative research process a qualitative expert reviewed the accuracy of the thematic extraction and analysis. The last phase in the process was sharing the results by transcribing the accounts of the participants and how they relate to the research question (Crabtree & Miller, 1999). Utilizing these steps helped to ensure that the data was analyzed and presented in a valid and representative manner.

**Ethical and Human Subjects Consideration**

Institutional Review Board (IRB) approval was obtained from both the University at Buffalo and RPCCC. Patients were not included in the research project but their ICGs were. Caregiver demographic information and identifiers were kept confidential. Collected data was kept on a password protected computer that only the PI had access to.

On the demographic form and Caregiver Self-Assessment form participants were asked to write the last four numbers of their phone number in place of their name or any identifying information. By doing so the participant demographics and responses on the Caregiver Self-Assessment form were correlated. The focus group sessions were audio recorded to ensure accurate data collection. For three years after the conclusion of this study, only the principal and co-investigator will have access to the tape recorder. The tape recorders are locked in the office of the co-investigator for a total of three years following the study, after which the tape recorder will be destroyed.

The focus group topics had the potential to invoke emotional distress that may have been difficult for some participants to cope with. A licensed social worker employed by RPCCC, who also runs the palliative care caregiver support group and BMT caregiver support group, agreed to make herself available to ICGs should they need further support. The social worker allowed the PI
to give out her contact information if caregivers became distressed or overwhelmed during the focus group.

**Recruitment Strategy**

The participants of the study were recruited from Roswell Park Comprehensive Cancer Center (RPCCC). The PI attended a BMT and palliative care caregiver support group to meet potential participants and inform them of upcoming focus groups. Information flyers were also placed in outpatient waiting areas for recruitment purposes. The participants were ICGs to an individual with an active cancer diagnosis or a personal history of cancer of any type or stage. The data that was analyzed using the Participant Demographics form (Appendix B) and the Caregiver Self-Assessment Questionnaire (Appendix C) that each participant completed. The Caregiver Self-Assessment Questionnaire consists of 16 yes or no responses that were quantitatively analyzed through descriptive statistics.

The Co-investigator emailed oncology APPs at cancer centers around the nation to inquire if they would be willing to participate in an email interview for this DNP project. Once APPs responded and were agreeable, the PI emailed with interview questions (Appendix E) regarding ICGs.

**Data Collection**

The qualitative component of this project was derived from conducting focus groups with the cancer ICGs who saw the focus group flyer and were willing to attend. Prior to participating in the focus groups, ICGs were asked to complete the demographic form and Caregiver Self-Assessment Questionnaire. The demographic forms and questionnaires were compared to correlate demographics to questionnaire responses. Qualitative questions (Appendix D) were developed with assistance from a qualitative expert to be used during the duration of the focus groups. Each
focus group session continued until saturation of the data was reached. The participants of the study consisted of adult caregivers of cancer patients who receive treatment at RPCCC.

Inclusion criteria consisted of being 18 years of age or older, English speaking, and an ICG to an individual with a current cancer diagnosis or a cancer survivor. Exclusion criteria included individuals less than 18 years of age, non-English speaking, and not being an active caregiver to an individual with cancer or a history of cancer.

**Data Analysis**

Qualitative research involves analysis of narrative data with the goal of identifying themes and patterns (Polit & Beck, 2011). Using this method of data analysis, the researcher breaks down data into smaller more manageable units to identify similarities and themes within the data. Data was analyzed by identifying major themes between different ICG focus groups. In order to identify the major themes, open coding was used. Open coding breaks down data into the words used by the study participants (Polit & Beck, 2011) For example, if multiple caregivers used the word “tired” it could be used as a code. If synonyms such as “fatigue” or “exhausted” appeared then a theme or category had been identified (Polit & Beck, 2011). The “trustworthiness” of qualitative analysis depends on the researcher’s ability to saturate the data to allow for transparency of data collection and sampling methods (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs, 2014). Preparedness prior to conducting research helps to improve data collection and participation of study participants, which contributes to a more robust and comprehensive data collection (Elo et al., 2014).

In qualitative studies the data stays true to the study participants and therefore is a direct representation of the study participant’s thoughts and responses (Neergaard, Olesen, Andersen, & Sondergaard, 2009). Questionnaires and focus groups, if analyzed correctly, provide
researchers and medical professionals with a large amount of information (Neegaard, Olesen, Andersen, & Sondergaard, 2009). Focus groups were utilized along with the Caregiver Self-Assessment Questionnaire in order to obtain the qualitative data needed. Focus groups allow researchers to better understand the data they are collecting and give researchers the opportunity to further expand on participant answers (Massey, 2011). Focus groups are similar to one-on-one interviews; however, focus groups are presented in a social setting and allow participants to converse, which provides a more robust and complete data collection (Massey, 2011). Massey (2011) suggests focus groups of six to twelve participants and one principal investigator (PI). The presence of the PI, along with the group dynamic, inspired thoughtful conversation pertaining to issues among the group members (Massey, 2011).

The Caregiver Self-Assessment questionnaire was utilized to collect quantitative data with permission from the Health in Aging Foundation. This questionnaire was created by the American Medical Association (AMA) as a tool to help caregivers and medical professionals to achieve an increased understanding of their behaviors and health risks as well as to identify caregivers who may require interventions (Health in Aging Foundation, n.d.). The questionnaire is available in four different languages and is generalizable to any ICG; therefore, the questionnaire applies to all ICGs, not just those caring for cancer patients (Health in Aging Foundation, n.d.). The questionnaire is composed of 18 questions: 16 questions are yes or no responses and two questions utilize a 10-point Likert scale (Health in Aging Foundation, n.d.). A scoring guide was provided at the end of the questionnaire. The scores of the questionnaire are used as a guide to identify caregivers who are most likely experiencing a high level of distress (Health in Aging Foundation, n.d.). The Caregiver Self-Assessment Questionnaire was tested and found to have a reliability coefficient alpha of 0.78 (Epstein-Lubow, Gaudiano, Hinckley,
Salloway & Miller, 2010). The questionnaire was then used to measure sensitivity and specificity as a tool to screen for depression. A score of 5 or more on the Caregiver Self-Assessment Questionnaire was found to be have a sensitivity of 0.98 and a specificity of 0.63 in identifying distress and depression (Epstein-Lubow, Gaudiano, Hinckley, Salloway & Miller, 2010). The questionnaire was identified as a reliable and valid tool to utilize when screening ICGs to identify possible distress and depression.

**Results**

A total of six informal cancer ICGs completed a Caregiver Self-Assessment Questionnaire; however, only five participants were available to participate in the focus group due to prior obligations. Two or three participants were present at each session. All of the participants presented voluntarily to the focus group session after seeing flyers advertising the DNP project throughout RPCCC. All participants in the study had an ill family member who received some aspect of their care at RPCCC. Of the total participants, three provided care to their family member after a stem cell transplant, two cared for patients with a Leukemia diagnosis, not yet requiring transplant, and one participant previously cared for her mother who passed away after battling brain cancer and also provided care to her aunt who had been newly diagnosed with breast cancer. The sample population consisted of three females and three males. Participant ages ranged from 32 to 62 years of age with the mean age of 50 years old. The median number of years spent being an informal caregiver among participants was 2.25 years. The number of hours spent caregiving per week ranged from a minimum of 30 hours per week to 168 hours per week. Five of the study participants admitted they had previous experience working in the healthcare field providing direct patient care. Four of the participants provided care to their spouse and two participants provided care to other members of their family.
Caregiver Self-Assessment Questionnaire

Based on scoring criteria provided by the Caregiver Self-Assessment Questionnaire, half of participants had a high degree of distress. The questionnaire recommends that these individuals seek medical care for a check-up as well as available caregiver resources such as a caregiver support group. The other half of study participants had a low level of distress based on scoring criteria.

The majority of participants answered yes to feeling like they could not leave their relative alone. Only one caregiver responded no to having difficulty making decisions. The rest of participants answered yes. Half of caregivers admitted to feeling completely overwhelmed, and the other half of caregivers answered negatively. Only one participant responded that they did not feel useful or needed over the past week. Half of participants admitted to feeling lonely over the past week, and the other half responded negatively to feeling lonely over the past week. Four participants felt upset that their family member changed from his/her former self. All but one participant felt like they were on edge or irritable over the past week. Four caregivers also admitted to sleep disturbances related to caregiving, and the same number of caregivers also admitted to having crying spells. Half of the participants responded yes to feeling a strain between work and family responsibilities while the other half responded no. Half of caregivers responded yes to having back pain, feeling ill, and being satisfied with family support. Five caregivers did not find their relatives living situation to be inconvenient or a barrier to care, and one participant choose not to answer. The last two questions of the survey utilized the Likert-scale. Question 17 asks “On a scale of 1 to 10, with 1 being “not stressful” to 10 being “extremely stressful,” please rate your current level of stress.” The mean response was 5.8 with 10 being the highest response and 3 being the lowest response. The final question of the survey
asks, “On a scale of 1 to 10, with 1 being “very healthy” to 10 being “very ill,” please rate your current health compared to what it was this time last year.” The average response was 4, the highest response was 8 and the lowest response was 3. Based on scoring criteria, a response of 6 or higher is an indicator of a high degree of distress.

*Focus Group Data Analysis*

**Isolation**

All but one participant alluded to feelings of isolation whether it be distance from home or lack of support. Two participants were Canadian and their home, family, and social supports were all a distance away from Roswell. They stayed in the Buffalo area for months isolated from their family and friends and are the only ICGs that have provided care for the patient. Caregiver one (CG1) stated that family and friends have been distancing themselves from herself and the patient. CG1 also mentioned that her family member requests that she stay at the hospital everyday, which further isolates her from obtaining potential support. Caregiver two (CG2) stated he has no ties to his home in Canada any longer and that his entire life is consumed by being the sole caretaker to his wife. Caregiver four (CG4) stated that no one helps her with caregiver responsibilities. Caregiver five (CG5) stated, “I feel so consumed with wanting to share this with her and wanting to help her...” CG5 went on to describe how he spent every night in the hospital with his wife for four consecutive months.

**Advocacy**

All of the focus group participants expressed the need to be an advocate for their loved one. All participants felt it was part of their duty as an ICG to be an advocate, to speak up during doctor visits, and to ask questions. CG1 expressed how she used to feel intimidated speaking to doctors, her fear of speaking hindered her ability to advocate for her husband. She became less
intimidated as time went on and felt she was a better caregiver because of this. CG1 shared an example of her advocacy when she explained how she once demanded a physician look at pictures that she had taken of her husband’s rapidly changing condition that resulted in a change of care. CG5 shared with the group his internal struggle with being an advocate for his wife. CG5 states “My biggest fear is getting upset with someone and them [RPCCC staff] taking it out on my wife. I just can’t afford to make these people hate her.” CG5 then went on to discuss how he constantly needed to be an advocate for his wife. He showed his internal struggle between the need to be an advocate and the fear that advocating would somehow impact the care his wife received.

**Internal Turmoil**

Most ICGs indicated during the focus group that they were struggling with their internal emotions. All of the ICGs became tearful during the focus group when describing their experiences as an ICG. Two of the participants made mention that the focus group session had been therapeutic for them. They stated more groups should be available to share their experiences with one another. CG3 stated that she felt helpless when it came to her husband’s diagnosis and stated, “this is something I can’t fix” expressing her fear, uncertainty, and lack of control over her husband’s diagnosis. She later went on to say “Sometimes, caregivers need care too” which expresses CG3’s concerns about other ICGs. CG4 also expressed overwhelming emotion when she described how she tries to stay strong and prevent other people from seeing that she is “breaking down”. She stated that she felt that she was a “strong” individual, but she also stated that sometimes “caregivers just get [feel] weak”. CG5 indicated that his wife’s mortality is a source of emotional turmoil for him when he stated “the part that scared me the most is not knowing when it is going to end. When she is going to take a turn for the worst.”
Guilt

More than half of the study participants specifically mentioned feelings of guilt when being away from their family member. CG1 expressed how she felt guilty during the duration of the focus group because she was not with her spouse. Her husband expressed how he wishes her to be with him all the time and how even minimal time away from him made her feel guilty. She also mentioned guilt outside the realm of not physically being with her husband. She stated that she felt like a “traitor” when she reported an issue to the medical team. She stated that her husband became upset with her for informing the health care team of a problem; however, as an ICG, she knew it was the appropriate decision. She described how difficult it was to see her husband so upset with her decision to contact his providers. CG3 expressed that she felt guilty when her husband is not feeling well, especially when she cannot be with him. She stated she has minimal time to take off work and cannot afford to stay home with him when he is not feeling well. CG4 related to CG3 when guilt was mentioned. CG4 also stated that she felt guilty leaving her family member even when her time away was spent at work and not for pleasure. She stated that she never really gets a break despite trying to balance caregiving, work, and time for herself.

Oncology Expert Interviews

Oncology experts, which included APPs such as nurse practitioners and physician assistants, from Dana-Farber Cancer Institute in Boston, Massachusetts, Fred Hutchinson Cancer Research Center in Seattle, Washington and Sarah Cannon in Nashville, Tennessee, were interviewed via email. The goal of the interviews was to identify the relationship these centers have with their informal caregivers and the resources they have available to them.

When asked how they identify unmet needs of caregivers, two experts expressed the importance of the role of the social workers. The APP from Sarah Cannon stated that providers
“rely heavily on the social worker to ensure our caregivers remain engaged and able.” Social workers at Sarah Cannon also provide additional resources based on caregiver needs and intermittent check-ins as needed. The APP from Dana-Farber mentioned that all transplant patients meet with a social worker prior to transplant, and based on ICG and patient needs, social workers will contact the patient and ICG on a regular basis. Most APPs expressed pitfalls in how caregiver needs are discovered and addressed. One APP stated “Depending on the complexity of the medical issues, there may be caregiver needs that aren’t identified or addressed.” Another APP stated “…I often forget to delve into the difficulties of being a full time caregiver…without a capable caregiver, the patients indeed will suffer. I believe we do an average job at supporting caregivers and wish there were more opportunities, organizations, or communities for additional resources”.

APPs were then questioned on the types of resources that are available for cancer ICGs at their specific institute. All APPs mentioned an ICG support group as an available resource. Two APPs mentioned online resources, and one APP specifically stated that they have a Facebook page for ICGs and patients with links to information and additional resources; however, the APPs did not further discuss the types of online resources they were referring to. An APP stated that a financial coordinator is available to help ICGs and patients navigate insurance and medical bills.

The APPs were also asked how members of the healthcare team keep in touch with ICGs. All APPs responded stating that they communicate with ICGs via telephone. The majority also mentioned using email as a main source of communication with ICGs. One APP mentioned that ICGs are often present at follow up visits and this is another opportunity they have to keep in touch with ICGs. An APP mentioned the use of their Long-Term Follow-Up Telemedicine
program that consists of nurses and a physician that work together to respond to emails and phone calls from patients and ICGs. After review of the three cancer center websites, more caregiver resources were discovered, which were not mentioned by the APPs that were interviewed. RPCCC, Dana-Farber, Fred Hutch, and Sarah Cannon were all found to have an abundance of caregiver resources available on their websites.

**Discussion**

Caregiver burden and unmet needs is not specific to cancer ICGs alone. As shown by the aforementioned studies, all types of ICGs may experience the burdens expressed by the participants of this project. ICG situations vary from person to person, which includes degree of burden and number of unmet needs. Each individual situation is different and unique such as the hours a week spent caregiving, to home life, work, and even the health status of caregivers. However, prior research and this DNP project have demonstrated that overall ICGs struggle with burden and unmet needs.

Although all types of ICGs may struggle with unmet needs, ICGs of cancer patients must deal with several experiences that are unique and specific to a cancer patient (Kent et al., 2016). For example, the inherent nature of cancer itself poses its own set of challenges. A cancer diagnosis can happen quickly and can derail patients and their families from their routine and daily comforts. Cancers are unpredictable which can lead to variable and vague symptoms contributing to increased stress, anxiety, and uncertainty for ICGs (Kent et al., 2016). Other types of chronic illnesses requiring an ICG often follow a set path and clinical timeline unlike the unpredictability of cancer (Kent et al., 2016).

As the number of cancer patients and survivors continues to grow across the United States so does the amount of ICGs (Kent et al., 2016) However, despite the growing population,
ICGs and their needs often go unnoticed by members of the health care team (Kent et al., 2016). ICG and patient well-being frequently go hand-in-hand; moreover, when an ICG is unwell, the patient is often unwell (Kent et al., 2016). Cancer care today is focused more on treatment and management on an outpatient basis, with fewer treatments requiring hospitalization (Sklenarova et al., 2015). The advancements in treatment and care are undoubtedly beneficial and with these advancements, patients rely heavily on their ICGs; therefore, ICGs now have a greater responsibility (Kent et al., 2016). Due to increased ICG responsibilities, it is imperative that healthcare providers offer opportunities for ICGs to express unmet needs and to provide resources of available support (Sharpe et al., 2005).

The Caregiver Self-Assessment Questionnaire was helpful in determining which ICGs were distressed and experiencing more unmet needs. For the majority of questions, half of the ICGs answered affirmatively and half of the ICGs answered negatively with their responses. Half of the participants had a high level of distress and half of participants had a low level of distress based on questionnaire scoring criteria. The split results may be related to the amount of support each ICG has. One of the statements on the questionnaire stated: During the past week or so, I have been satisfied with the support my family has given me. The split results most likely are related to the limited sample population and may not be reflective of the vast majority of ICGs. Half of the ICGs responded affirmatively to this statement and the other negatively. The ICGs who responded affirmatively to this statement had a high level of distress. This corresponds to the literature that reports limited support networks lead to increased distress when compared to those with more family and social support (Armoogum, Richardson, & Armes, 2013). The Theory of Caregiver Stress identifies social support as a factor or input that directly influences an ICGs perceived level of distress. If an ICG perceives their social supports to be positive, then
their support reduces perceived stress by changing cognitive appraisal. Consequently, if perceived social support is minimal then there will be an increase in perceived stress (Tsai, 2003). The Theory of Caregiver Stress relates to this project as the project aims to identify unmet needs. Unmet needs can be identified as inputs; inputs compile leading to increased distress and depression, which is then portrayed as poor outcomes.

A study performed in 2012 identified four major theme related to ICGs. These themes were identified as a decline in health, role conflict, lack of support, and faith as an alleviating factor (Bialon & Coke). These themes presented by Bialon and Coke support the themes and data collected for this DNP project. Several questions on the Caregiver Self-Assessment Questionnaire address perceived decline in ICG health. More specifically, five questions addressed perception of emotional health. The majority of participants answered affirmatively to these questions that proved they were experiencing a decline in emotional well-being. Guilt and internal turmoil were also themes that were identified during focus group discussion. Both of these themes correspond to poor emotional health and the emotional toll caregiving can have on an individual. In 2012, a similar qualitative study using ICGs also identified decline in overall health, which included emotional health. Emotional turmoil was a major theme that was identified among ICGs during the focus groups. The majority of the ICGs expressed feelings of guilt associated with caregiving. Guilt can have a negative impact on ICG health that leads to patient distress (Bialon & Coke, 2012). In 2016, Kent et al., supported this statement through research findings affirming that health outcomes of patients and ICGs are often related (Kent et al., 2016).

This DNP project addressed not only emotional health but also physical health as well. The Caregiver Self-Assessment Questionnaire specifically asked three questions related to
caregiver physical health. More than half of participants agreed that they were experiencing sleep disturbances related to caregiving. Exactly half of participants admitted to having back pain and feeling ill within the past week. Bialon and Coke identified that almost all ICGs reported a chronic lack of adequate sleep and some also reported disrupted sleep (2012). Some of the top unmet needs of ICGs discovered by Armoogum, Richardson, and Armes were receiving emotional support, balancing patient needs with personal needs, and personal health (2013). All needs identified in this DNP project corresponded with Bialon and Coke in 2012.

According to Bialon and Coke, role conflict appears as a major theme among ICGs (2012). However, in contrast to the previously mentioned study, this DNP project did not specifically identify role conflict as a main theme among ICGs. The difference may be due to a number of factors such as the small sample size, limited population, or time spent caregiving. Although role conflict was not a major theme that was extracted from the data, some caregivers did make mention of the difficulty balancing their various roles such as their work and personal life while being an ICG.

Email interviews with AAPs from Dana-Farber Cancer Institute in Boston, Massachusetts, Fred Hutchinson Cancer Research Center in Seattle, Washington and Sarah Cannon in Nashville, Tennessee gave insight into provider-caregiver relationships and available caregiver resources. APP responses highlight the disparity between ICGs and APPs, the literature helps to prove the disassociation when interviewing these APPs. APPs do not address ICG needs on a regular basis and do not make it a priority, although they admit to being aware of the stress involved with caregiving. The interviewed APPs stated that they are aware that ICGs carry a heavy burden and that ICG issues are not always properly addressed. Of the resources mentioned in these interviews, not one provider alluded to APP presence during or affiliation to any of these
resources. The APPs mentioned the important roles of mostly nurses and social workers when it comes to ICG needs. The literature proves that that ICG-provider relationship is crucial. Further proven by Buchanan, Radin, and Huang, more than 30% of ICGs needed but neglected to ask for respite services, and about 25% of ICGs reported the need to seek mental health services but less than one third actually sought out professional help (2011). These statistics emphasize the need for APPs to be vigilant and assess ICGs for potential unmet needs. Directly questioning ICGs on what they struggle with can provide APPs with an abundant amount of information to suggest beneficial resources. APPs must be attuned to ICG needs and increase involvement in resources to help build and strengthen rapport with ICGs.

The interviewed APPs mentioned various ICG resources that are available at their respective institutes; however, after further research on institute websites, additional ICG resources were discovered. Dana-Farber Cancer Institute has a page on their website dedicated to ICG resources. The APP interviewed from Dana-Farber did not mention a number of the additional resources that the institute has available to their ICGs, which shows that many APPs may not know all the potential resources available to ICGs. For example, psychiatrists are available to provide emotional support to ICGs of cancer patients at Dana-Farber (Dana-Farber Cancer Institute, n.d.). Spiritual care support and counseling are available at both Dana-Farber Cancer Institute and RPCCC. Information on supportive care for patients and ICGs was not identified by the APPs or on the websites of Sarah Cannon or Fred Hutchinson Cancer Research Center. Faith and spiritual care can be a form of support, intervention, or resource to ICGs to decrease their degree of distress (Bialon & Coke, 2012). Research has found faith and spiritual care to be an alleviating factor to the burden of caregiving (Bialon & Coke, 2012).
Sarah Cannon’s website mentions nurse navigators, which are nurses who coordinate care for patients and ICGs among the multiple disciplines. They also provide support by linking caregivers to resources and meeting in person with ICGs if warranted (Sarah Cannon, n.d.). In 2015 the top ten unmet needs of ICGs were identified, and one of the top needs mentioned by ICGs was wanting to feel confident that care is being coordinated among team members (Sklenarova et al., 2015). The use of nurse navigators at Sarah Cannon will help to alleviate some degree of burden and limit this unmet need. Cancer centers around the nation should be utilizing similar programs.

All of the APPs from cancer centers discussed the use of support groups, whether it be online or in person. The goal of a support group is to bring ICGs together to support each other and enhance feeling of community, support, and emotional stability. Of note, Fred Hutchinson’s support group page on their website is no longer available, which makes it unclear if they are currently offering support groups (Fred Hutchinson, n.d.). Despite having active support groups available at RPCCC, the surveyed ICGs still feel burdened with their emotions and lack of support. According to the licensed social worker who helps run the support groups at RPCCC, there is minimal attendance and it is often difficult to find routine participants. This DNP project highlights there is still a gap in practice when it comes to identifying ICG needs and how to connect ICGs to resources. There is an abundance of resources available to ICGs at RPCCC and within the community. The themes that were uncovered by the ICGs identified the need for greater emotional support, although there are several resources available directed toward emotional care. There is an identified disconnect between ICG unmet needs and linking ICGs to appropriate resources. Park et al. discovered that ICGs are aware that they need support through
resources, but often, do not receive the support they need which could be related to difficulties connecting ICGs to resources (2010).

A potential ICG benefit as a result of this capstone project is increased support through identification of current needs and resources. Park et al. conducted a survey and the results revealed that ICGs are aware that they need support, but the majority are not receiving the support they need (2010). In order to resolve this issue, a compendium of local community and online resources is provided (Appendix F) along with a list of available resources at RPCCC (Appendix G). The objective was to increase awareness of available resources, in order to link ICGs with appropriate tools to minimize burden. This would decrease ICG stress, and subsequently improve health outcomes of patients.

**Strengths and Limitations**

Limitations of the project include a small sample population of ICGs whose loved ones receive care at RPCCC. Massey (2011) suggests focus groups of six to twelve participants and one PI. Unfortunately, due to restricted recruitment there were only two or three participants in a focus group at a time. Recruitment was restricted to informational flyers in common areas of RPCCC per the Roswell IRB. Due to the small sample size, data saturation may have been reached more quickly than if the population was larger. Another project weakness includes time constraints. Many ICGs are pressed for time and may not have the available time to participate in the project. As demonstrated by the literature and this DNP project, ICGs may experience feelings of embarrassment or guilt associated with feeling inadequate or overwhelmed with providing care and may be reluctant to express these feelings outwardly; however, some ICGs did also express this openly. The PI is employed at RPCCC, which may have discouraged some ICGs from
attending focus groups out of fear of having to interacting with the PI in the clinical setting, which is also a potential downfall to the recruitment strategy.

An evident strength of the study is the design. A mixed-methods approach to data collection combines qualitative and quantitative data that allows for a thorough and robust data pool when compared to qualitative or quantitative data collection alone. Interviewing APPs at various cancer centers around the nation gave further insight into available resources and the ICG-provider relationship.

The PI is an employee at RPCCC on the inpatient Leukemia unit and cares for patients and their family members while they are admitted to the hospital. The PI has cared for many patients prior to receiving their BMT, and has witnessed first-hand the daily strain that caregiving can place on an individual or entire family unit. The majority of study participants provided care to a patient with Leukemia or a history of a BMT. This strengthens the study as the PI’s previous knowledge of these cancer types and treatments allowed the PI to fully understand the points the participants were trying to convey, while allowing for a fluid and effortless conversation.

**Future Recommendations**

All but one of the ICGs that participated in the DNP project has had previous experience with hands on patient care. Individuals with formal patient care have distress and unmet needs; therefore, an assumption is made that those without previous experience may have additional distress and unmet needs when compared to ICGs with previous patient care experience. Future studies should compare ICGs with formal direct patient care experience to those without formal training. Further research could compare the differences in unmet needs and perceived burden between these two caregiver groups.
The purpose of this DNP project was to identify the unmet needs of ICGs at RPCCC and then make recommendations to provide additional resources based on resources at other cancer centers. To further enhance and ensure ICGs have the tools that they need, this project also provides a compendium of established community resources for ICGs; however, this DNP project has shown that ICGs have many resources available to them that address the unmet needs they expressed. Future research must explain why ICGs are still dealing with a variety of unmet needs and experiencing high levels of distress despite available resources. Further research is also necessary to determine if the current resources available are beneficial. If ICGs are aware of these resources, and what barriers, if any, prevent ICGs from utilizing these resources.

**Contributions to Practice**

As shown through the literature and this study, ICGs suffer within the healthcare system. ICGs deal with many unmet needs on a regular basis and try to manage their multiple roles. Although the sample size of this project was small, the data defends the literature. Major unmet needs of ICGs that were identified in this project were both physical and emotional support. When APPs were asked about how they identify unmet needs of ICGs, most acknowledged that they struggled in providing adequate resources. This DNP project identifies and makes ICG resources known as demonstrated by Appendix F and Appendix G. Many ICGs and providers may not be aware of the resources that are available. ICGs may not know of available resources provided by RPCCC or the local community. Both Appendix F and Appendix G identify local resources which can be used to help ICGs meet some of their needs. By simply questioning ICGs about the challenges they face, providers could enhance their knowledge of their ICGs burden, and build a strong rapport by providing beneficial resources. Identification of unmet
needs and access to resources will provide the opportunity to decrease burden and enhance ICG and patient outcomes alike.
References


longitudinal study in alzheimer caregivers. *Psychosomatic Medicine, 79*(7), 735-741. doi:10.1097/PSY.0000000000000497


Appendix B

Participant Demographics

Last 4 digits of telephone number _ _ _ _

1. Age_______
2. Race____________
3. Gender__________
4. Relationship to patient receiving care___________________________
5. How long have you been an informal caregiver? _______________
6. How many hours per week on average do you spend caregiving? __________
7. Have you ever worked in the healthcare field providing direct patient care (eg. Nurse, nurses aid, physician, etc.)? ____________________
Appendix C

Caregiver Self-Assessment Questionnaire

Caregivers are often so concerned with caring for their relative’s needs that they lose sight of their own wellbeing. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>1. Had trouble keeping my mind on what I was doing</td>
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<tr>
<td>2. Felt that I couldn’t leave my relative alone</td>
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<td>3. Had difficulty making decisions</td>
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<tr>
<td>4. Felt completely overwhelmed</td>
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<td>5. Felt useful and needed</td>
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<td>6. Felt lonely</td>
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<td>7. Been upset that my relative has changed so much from his/her former self</td>
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<td>8. Felt a loss of privacy and/or personal time</td>
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<td>9. Been edgy or irritable</td>
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<td>10. Had sleep disturbed because of caring for my relative</td>
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<tr>
<td>11. Had a crying spell(s)</td>
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<tr>
<td>12. Felt strained between work and family responsibilities</td>
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<td>13. Had back pain</td>
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<td>14. Felt ill (headaches, stomach problems or common cold)</td>
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<td>15. Been satisfied with the support my family has given me</td>
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<td>16. Found my relative’s living situation to be inconvenient or a barrier to care</td>
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<tr>
<td>17. On a scale of 1 to 10, with 1 being “not stressful” to 10 being extremely stressful, please rate your current level of stress.</td>
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<tr>
<td>18. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “very ill,” please rate your current health compared to what it was this time last year.</td>
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</tbody>
</table>

Comments:
(Please feel free to comment or provide feedback)

For additional tools for caregiving or aging, visit www.CaregiversLibrary.org

Appendix D

Qualitative Focus Group Questions

1. Let's all go around the group and tell us your relation to your loved one you are helping and what types of activities you do for them or help them with on a daily basis?

2. Can you describe what you do for your loved one in 1-2 words?

3. Can anyone describe some of the personal impacts they have experienced since beginning to provide this type of care for their loved one?

4. What aspect of providing care is most problematic for your or what keeps you up at night?

5. How do you get the information you need to provide care?

6. What helps you to continue to do what it is that you are doing?

7. Do you have support?

8. Are there financial concerns connected with caregiving?

9. Is there anything that I should know about caregiving from your point of view that we have not discussed?
Appendix E

Qualitative Email Interview Questions

1. How Do you or members of the healthcare team identify unmet needs of your patient’s caregivers?

2. What kind of resources are available for cancer caregivers at your institute?

3. How do you or members of the healthcare team keep in touch with the caregivers?
Appendix F

Western New York and Online Community Resources

Support Groups:

- American Cancer Society Support Group 1-800-227-2345
- Caregivers (716) 636-3055 Ext. 3129
- Family Caregivers Support Group 716- 648-2820
- Well Spouse Association (For supportive spouse / partner of chronically ill, disabled.) 716-912-2075
- 4th Angel Patient & Caregiver Mentoring Program 866-520-3197
- CanCare 866-461-0028
- Friend for Life Cancer Support Network 866-374-3634
- CancerCare 800-813-4673

Online Communities

- Lotsa Helping Hands www.lotsahelpinghands.com
- Next Step in Care www.nextstepincare.org
- Cancer Experience Registry-Caregiver
  - www.cancersupportcommunity.org or 1-888-793-9355
- Cancer Support Community www.cancersupportcommunity.org
  - Helpline: 1-888-793-9355
- CaringBridge www.caringbridge.org
- Be The Match Caregiver’s Companion Program
  - patientinfo@nmdp.org or 1-888-999-6743

Transportation:

- American Cancer Society Road to Recovery Program 1-800-227-2345
- Erie county and The City of Buffalo (senior van service)
- Medicaid transportation in Western New York (1-800-850-5340
- Niagara Frontier Transportation Authority (NFTA) 716-855-7268
- Love In The Name of Christ (Love INC) 716-532-3541
- Caring Harts Transport, Inc 716-457-3051

Housing:

- Cancer Support Community Airbnb 877-793-0498

Financial:

- HeartShare Human Services of New York (Utility Assistance) 855-852-2736
- The Bone Marrow Foundation 800-365-1336
• Mission4Maureen (brain cancer) 440-840-6497
• Centers for Medicare & Medicaid Services www.cms.gov
• Benefits.gov 800-333-4636
• Hill-Burton Program 877-543-7669
• CancerCare 800-813-4673
• WISER (Women’s Institute for a Secure Retirement) www.wiserwomen.org
• Leukemia & Lymphoma Society Co-Pay Assistance Program 1-877-557-2672
• Leukemia & Lymphoma Society Travel Assistance Program 844-565-2269

General:

• Cleaning for a Reason 877-337-3348
• Family Caregiver Alliance www.caregiver.org/node/3831
• Caregiver Action Network www.caregiveraction.org
• National Transitions of Care Coalition www.NTOCC.org
• National Cancer Institute www.cancer.gov
• Help for Cancer Caregivers www.helpforcancercaregivers.org
• Be The Match www.bethematch.org
• Pancreatic Cancer Action Network www.pancan.org or 877-573-9971
Appendix G

Caregiver Resources Currently Available at RPCCC

- Adolescent and Young Adults Program
- Women’s Resource Center
- Cancer Information Services (1-800-Roswell)
- Financial Counselors (716-845-4782)
- Legal Care
- Music and Arts in the Lobby Program
- Nutrition
- Patient Advocate Program
- Pet Therapy Program
- Psychosocial Oncology
- Resource Center
- Roswell Park Online Community
- Support Groups
  - Bladder Cancer Support Group (4th Tuesday of every month)
  - Breast Cancer Support Group (1st Wednesday of every month)
  - General Survivor and Caregiver Support Group (3rd Thursday of every month)
  - Head and Neck Cancer Support Group (3rd Wednesday of every month)
  - Leukemia, Lymphoma & Hodgkin’s Disease Support Group (last Thursday of every month)
  - Lung Cancer and Lung Cancer Caregivers Group (2nd Wednesday of every month)
  - Melanoma Support Group (1st Monday of every month)
  - Multiple Myeloma Support Group (4th Wednesday of every month)
  - Ostomy Support Group (2nd Wednesday of every month)
  - Transplant & Cellular Therapy Patient/Caregiver Support Group (1st Wednesday of every month)
  - Young Breast Cancer Support Group (3rd Wednesday of every month)
  - Community Bereavement Group (1st & 3rd Wednesday of every month, 2nd Thursday of every month, 4th Tuesday of every month)
- Spiritual Care
- Volunteer Desk
- Local Lodging
  - Kevin Guest House
  - McDonald House
  - Comfort Suites
  - Best Western
  - Adams Mark
  - Wyndham Garden Hotel
- Discounted Parking ($4 max/day)
Dear Jamie Kohl, FNP,

Thank you for your interest in HealthinAging.org, and for your inquiry about the “Caregiver Self-Assessment Questionnaire” (2015) tip sheet, for use in the following way:

- Inclusion in research project involving Caregivers of Cancer Patients, as part of Doctorate Capstone project at the University at Buffalo.

**Permission is granted for the above provided that:**

1. Permission to reprint and distribute (if applicable) the “Caregiver Self-Assessment Questionnaire” (2015) tip sheet, is limited to use in the above stated manner only. Rights do not apply to revised editions. Edits or translations to the material are not allowed. Rights apply to print/hardcopy only; website electronic rights do not apply.

2. The Society does NOT endorse companies, products or services, and strictly prohibits any suggestion of endorsement, recommendation, or superiority of one company, product or service over another company, product or service.

If you’ve any further questions, please feel free to contact me at egallagher@americangeriatrics.org.

Sincerely,

Elisha Medina-Gallagher
Manager, Special Projects
American Geriatrics Society
October 22, 2018

Dear Jamie Kohl:

On 10/22/2018, the IRB reviewed the following submission:

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<td>Methods Approach to Identify Needs</td>
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<td>Jamie Kohl</td>
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<tr>
<td>IRB ID:</td>
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<td>• Consent Form, Category: Consent Form;</td>
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<tr>
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<td>• Signed letter of support .pdf, Category: Other;</td>
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<tr>
<td></td>
<td>• Study Informational Flyer.pdf, Category: Recruitment Materials;</td>
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</table>

The IRB approved the study from 10/22/2018 to 10/21/2019 inclusive. Before 10/21/2019 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.

If continuing review approval is not granted before the expiration date of 10/21/2019, approval of this study expires on that date. The Initial Study materials for the project referenced above were reviewed and approved by the SUNY University at Buffalo IRB (UBIRB) by Initial Study Review. Before to 10/21/2019 inclusive. Before 10/21/2019 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.

If continuing review approval is not granted before the expiration date of 10/21/2019, approval of this study expires on that date. or within 30 days of study closure, whichever
is earlier, you are to submit a continuing review application with required explanations. You can submit a continuing review application by navigating to the active study in Click IRB and clicking Create Modification / Continuing Review. Studies cannot be conducted beyond the expiration date without re-approval by the UBIRB.

In conducting this study, you are required to follow the requirements listed in the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library within the IRB system.

UB IRB approval is given with the understanding that the most recently approved procedures will be followed and the most recently approved consenting documents will be used. If modifications are needed, those changes may not be initiated until such modifications have been submitted to the UBIRB for review and have been granted approval.

Prior to the expiration of this approval, you will receive notification that it is time for the UBIRB to conduct its periodic review of your study. Studies cannot be conducted beyond expiration date without re-approval by the UBIRB.

As principal investigator for this study involving human participants, you have responsibilities to the SUNY University at Buffalo IRB (UBIRB) as follows:

1. Ensuring that no subjects are enrolled prior to the IRB approval date.
2. Ensuring that the study is not conducted beyond the expiration date without re-approval by the UBIRB.
3. Ensuring that the UBIRB is notified of:
   • All Reportable Information in accordance with the Reportable New Information Form Smart Form.
   • Project closure/completion by the Continuing Review/Modification/ Study Closure smart form.
4. Ensuring that the protocol is followed as approved by UBIRB unless a protocol amendment is prospectively approved.
5. Ensuring that changes in research procedures, recruitment or consent processes are not initiated without prior UBIRB review and approval, except where necessary to eliminate apparent immediate hazards to subjects.
6. Ensuring that the study is conducted in compliance with all UBIRB decisions, conditions, and requirements.
7. Bearing responsibility for all actions of the staff and sub-investigators with regard to the protocol.

8. Bearing responsibility for securing any other required approvals before research begins.

If you have any questions, please contact the UBIRB at 716-888-4888 or ub-irb@buffalo.edu.
November 7, 2018

Jamie Kohl, RN, BSN
jamie.kohl@roswellpark.org

Dear Ms. Jamie Kohl:

On 11/7/2018, the IRB Office reviewed the following submission:

<table>
<thead>
<tr>
<th>Type of Review:</th>
<th>Initial Study</th>
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<tbody>
<tr>
<td>Title of Study:</td>
<td>Unmet Needs of Informal Cancer Caregivers: A Mixed-Methods Approach to Identify Needs</td>
</tr>
<tr>
<td>Investigator:</td>
<td>Jamie Kohl, RN, BSN</td>
</tr>
<tr>
<td>IRB ID:</td>
<td>STUDY00000806 / IRB 080618</td>
</tr>
<tr>
<td>Funding:</td>
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<td>Grant ID:</td>
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<td>IND, IDE, or HDE:</td>
<td>None</td>
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<tr>
<td>Documents Reviewed:</td>
<td>• Informational Flyer, Category: Recruitment Materials; • Focus Group Outline .pdf, Category: Recruitment Materials; • Caregiver Self-Assessment Questionnaire, Category: Recruitment Materials; • IRB Approved Protocol , Category: IRB Protocol; • Participant Demographics.pdf, Category: Recruitment Materials; • Eligibility Screening.pdf, Category: Recruitment Materials; • Consent , Category: Consent Form;</td>
</tr>
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</table>

The external IRB’s approval for this study will expire on 10/21/2019.

Please be advised that only the Roswell Park stamped consent form can be used to enroll subjects.

As a reminder, this research project is subject to approval by the external IRB, but also requires acceptance by the Roswell Park IRB prior to initiation by the investigator. Please promptly notify the local IRB office upon:

1) Any new Unanticipated Problems or any other Reportable New Information
2) Any new or updated information regarding potential Conflict of Interests
3) Any changes in local study team members

4) Notification of renewal by the reviewing IRB. A progress report must be submitted to the ORSP at least ten days prior to the expiration date noted above for continuing review.

5) Any modifications/updates in the research project

6) Closure of the Study

The principal investigator is responsible for ensuring that the research complies with all applicable regulations. The Roswell Park IRB reserves the right to stop the research for violations of regulatory or IRB requirements.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103), including the reporting of Unanticipated Problems and any other Reportable New Information.

Sincerely,
Donald Handley MSc, MBA
UNMET NEEDS OF INFORMAL CANCER CAREGIVERS: A MIXED METHODS APPROACH TO IDENTIFY NEEDS

Jamie Kerner
University at Buffalo
Spring 2019
School of Nursing

UNMET NEEDS

DNP Project Purpose

- Identify unmet needs of informal cancer caregivers at Roswell Park Comprehensive Cancer Center
- Provide a compendium of local community caregiver resources
- Recommend additional resources to Roswell that are utilized by other cancer centers throughout the nation

Study Questions

What are the unmet needs of informal cancer caregivers within the Roswell Park Comprehensive Cancer Center community?

What resources could be implemented to improve caregiver outcomes and decrease burden and unmet needs?

Informal Caregiver Defined

- Informal caregivers (ICGs) are defined as someone who provides a significant amount of care to an individual over a period of time usually months to years (Kent et al., 2016)
- Usually ICGs are unpaid and are a family member or friend of the patient
Caregiver Burden Defined

“Any physical and emotional reaction to the imbalance of demands placed on the caregiver, including time, multiple roles, physical and emotional states, financial resources, and informal care resources” (Bialon & Coke, 2012, p. 210).

Background & Significance

- 14.5 million cancer survivors in the United States (Kent et al., 2016).
- The number of cancer survivors is estimated to increase to 20.3 million by the year 2026 (American Cancer Society, 2016).
- Majority of care is provided in the home by informal caregivers (Adelman et al., 2014).
- 43.6% of cancer caregivers had at least 1 unmet need (Sklenarova et al., 2015).
- Caregiver outcomes directly impact patient outcomes (Kent et al., 2016).
- Many caregivers admit to a lack of knowledge, support or self-confidence to provide proper care (Kent et al., 2016).
- Caregivers often experience feelings of being lost or without adequate support (Adelman et al., 2014).
- Health outcomes of both provider and caregiver are directly related (Adelman et al., 2014).
- The longer an ICG provider cares to an individual the lower their reported quality of life (Boston & Coke, 2012).

Risks for Developing Caregiver Burden:

- Financial stress
- Social isolation
- Time spent caregiving/length of time caregiving
- Type of care provided
- Lack of support
- Gender

(Adelman et al., 2014)
## Background & Significance

- Informal caregivers play a pivotal role in identifying health-related concerns and changes, addressing them as soon as possible.
- Without informal caregivers, patients would suffer from poorer outcomes.
- More often than not, caregivers are overworked, left with a lack of knowledge, support, and a heavy burden.
- If caregivers are supported, given knowledge, and confidence to be a caregiver, perhaps patient outcomes would improve. For this reason, it is imperative that the caregiver needs at Roswell Park are evaluated to decrease the burden.

## Middle-Range Theory of Caregiver Stress: Theory Inputs

- Focal: Related to responsibilities associated with caregiving
- Contextual: Stressful life events unrelated to caregiving
- Residual: Uncontrollable demographic information

## Middle-Range Theory of Caregiver Stress: Theory Outputs

- Physical Function
- Self-esteem/Mastery
- Role Enjoyment
- Marital Satisfaction

## Theoretical Framework

**Middle-Range Theory of Caregiver Stress:**
- Derivative of Roy’s Adaptation Model
- Developed in 1984
- Based on inputs that control outputs (cause and effect)

(Tsai, 2003)
Theoretical Structure

Objective burden
Stressful life events
Social support
Social rules
Race
Age
Gender
Relationship with the care receiver
Perceived caregiver stress
Depression
Physical function
Self-esteem/master
Role enjoyment
Marital satisfaction

Input
Control Process
Output

Theory Justification

• The theory describes how inputs or factors are related to outcomes
• Focal inputs are identified as unmet needs of caregivers
• The more focal inputs, the poorer the health outcomes
• If focal inputs are removed or minimized, outcomes improve

Methods

• Mixed methods design utilizing descriptive statistics and thematic analysis
• Informal caregivers at Roswell Park participated in a focus group and completed the Caregiver Self-Assessment Questionnaire
• Oncology experts at cancer centers around the nation responded to email interviews

Study Sample

Focus Group/Questionnaire Sample
• Adult (age 18-75) informal caregivers of cancer patients at Roswell Park Comprehensive Cancer Center (n=6)

Email Interview Sample
• Advanced practice oncology providers
• 2 Nurse Practitioners
• 1 Physician Assistant
Focus Group Eligibility
- Age 18 years or older
- Informal caregiver to a patient with a current cancer or previous cancer diagnosis
- English speaking

Recruitment Strategy
- The principal investigator (PI) approached two cancer support groups at Roswell Park to inform potential participants about the upcoming focus group.
- Information flyers were dispersed in waiting areas at Roswell Park.
- The co-investigator reached out to advanced practice providers at cancer centers around the nation to ask if they would be willing to participate in the DNP project.
- Once the advanced practice providers agreed, the PI reached out to the providers via email with interview questions.

Qualitative Data Collection
- Focus group consists of the PI and informal caregivers who love a patient receiving care at Roswell Park.
- Focus group questions were developed based on the questionnaire and study purpose.
- The PI reviewed the group with a topic only when participants have reached topic saturation or longer are contributing discussion.
- Focus group continued until saturation of data was reached, which was about one hour.

Focus Group Questions
1. What types of activities do you do for your loved one or help them with on a regular basis?
2. Can you describe what you do for your loved one in 1-2 words?
3. Can anyone describe some of the personal impacts they have experienced as a result of providing this type of care for their loved one?
4. What aspects of providing care are most problematic for you or keep you up at night?
5. How do you get the information you need to provide care?
6. What helps you to continue to do what you are doing?
7. Do you have support?
8. Are there financial concerns connected with caregiving?
9. Is there anything that should be taught or improved from your perspective that we have not discussed?
Email Interview Questions

1. How do you or members of the healthcare team identify unmet needs of your patients?
2. What kind of resources are available for cancer caregivers at your institution?
3. How do you or members of the healthcare team keep in touch with caregivers?

Quantitative Data Collection

- The Compassion Fatigue Resilience Questionnaire developed by the American Academy of Association (AHA) was used with copyright permission.
- Research includes a pre-existing tool to be validated and used in a research setting for stress and depression (Spitali, Luhr, and Miller, 2019).
- The questionnaire is comprised of 16 yes/no responses and questions that utilize the 10-point Liker scale (Health in Aging, n.d.).
- Scoring guide by the AMA is provided.

Ethical and Human Subjects Consideration

- Institutional review board (IRB) approvals were obtained from both the University at Buffalo and Roswell Park.
- No written identifying participant information participants used their last digit of their social security number to correlate demographic information with the questionnaire.
- Tapes recordings will be kept in a locked cabinet within the investigator’s office and University audits for 3 years and then destroyed.
- A licensed social worker employed at Roswell has agreed to assist the PI in distributing her contact information should a participant experience emotional distress due to conversation topics.

Focus Group Results

- Five total focus group participants.
- Two male participants and three female participants.
- All participants were asked to select a family member being treated at Roswell Park for a cancer diagnosis.
- A total of two focus groups were held.
- Focus groups were held in a private conference room within Roswell Park.
- Both focus groups were held at a location of the investigator's choice.
Focus Group Results

- Four themes were identified:
  - Isolation
  - Advocacy
  - Internal turmoil
  - Guilt

Isolation
- All but one participant expressed feeling isolated from family or friends.
- Two participants noted a lack of family support.
- Two participants discussed how time in the hospital distances themselves from family and friends.

Advocacy
- All participants mentioned advocacy as a caregiving responsibility.
- Two participants struggled with advocating for themselves.

Internal Turmoil
- All participants became tearful at some point during the focus group.
- Two participants noted that the focus group had been therapeutic.
- More support groups should be made available.
- Participants described feelings such as helplessness, weakness, loss of control, fear, and uncertainty.

Guilt
- More than half of participants mentioned feelings of guilt.
- Most of the guilt was a result of not physically being present with the patient.

Focus Group Results

- All participants were bone marrow transplant providers.
- Two nurses practitioners and one physician assistant.
- To a total of 3 participants, 2 nurse practitioners and one physician assistant.

Email Interview Results
UNMET NEEDS

Identifying Unmet Caregiver Needs

- The majority of the responsibility falls on the social worker.
- Not true caregiving responsibilities fall on the provider.
- "Depending on the complexity of the medical issues, there may be caregiving needs that aren’t identified or addressed.
- "I often forget to delve into the difficulties of being a full-time caregiver...without a capable caregiver, the patient indeed will suffer.
- "I believe we do an average job at supporting caregivers and wish there were more opportunities, organizations, or communities for additional resources.

Available Resources

- All participants mentioned support groups.
- Two participants mentioned online resources but did not specify further.
- One participant mentioned a financial consultant to help navigate medical expenses.

Keeping in Touch with Caregivers

- All participants mentioned communication in telephone.
- Majority of participants use email as a form of communication with caregivers.
- One participant mentioned communication with caregivers when they present with the patient for follow-up appointments.

Caregiver Self-Assessment Questionnaire Results

- Six total participants, only one participant completed the questionnaire but did not stay for the focus group.
- Population consisted of three females and three males.
- Participants ranged from 32 to 62 years old with an average age of 50.
- Median number of years as a caregiver was 2.25 years.
- Number of hours spent caregiving a week ranged from 30 hours to 168 hours.
- Five participants provide care to a spouse, two participants provide care to other members of their family.
UNMET NEEDS

raseased half of participants (n=3) had a high degree of distress, and half of participants (n=3) had a lower degree of distress.

- Felt like they could not leave their family member alone (n=4)
- Felt completely overwhelmed (n=3)
- Felt useful or needed over the past week (n=5)
- Felt lonely (n=3)
- Felt on edge or irritable (n=5)
- Sleep disturbance related to caregiving (n=4)
- Strain between work and family (n=3)
- Back pain (n=3)
- Felt ill in past week (n=3)
- Satisfied with family support (n=3)

On a scale of 1 to 10, with 1 being “not stressful” and 10 being “extremely stressful,” please rate your current level of stress.

- Responses ranged from 3 to 10
- Mean response was 5.8

On a scale of 1 to 10, with 1 being “very healthy” and 10 being “very ill,” please rate your current health compared to what it was this time last year?

- Responses ranged from 3 to 8
- Mean response was 4

The number of cancer patients and subsequently informal caregivers continues to grow across the nation.

Cancer care today favors treatment as an outpatient whenever possible.

Previous research findings have shown informal caregivers are overwhelmed with stress and other burdens, leading to burnout and other negative outcomes. Despite this, many caregivers continue to provide care, often sacrificing their own health and well-being.

Despite a large number of caregiver support groups being available within the community, and on the internet, not all caregivers are aware of these resources or know how to access them.

In a recent study, participants were asked to rate their awareness of different support groups.

- Responses ranged from 1 to 6
- Mean response was 4

Discussion

- The number of cancer patients and informal caregivers continues to grow across the nation.
- Cancer care today focuses on treatment as an outpatient whenever possible.
- Previous research findings have shown informal caregivers are overwhelmed with stress and other burdens.
- Despite the availability of support groups, caregivers may not be aware of these resources or know how to access them.

Cancer care today favors treatment as an outpatient whenever possible.

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- Mean response was 4

Discussion

- The number of cancer patients and informal caregivers continues to grow across the nation.
- Cancer care today focuses on treatment as an outpatient whenever possible.
- Previous research findings have shown informal caregivers are overwhelmed with stress and other burdens.
- Despite the availability of support groups, caregivers may not be aware of these resources or know how to access them.
UNMET NEEDS

Discussion

- Half of study participants still experience a high level of distress related to caregiving, despite numerous resources
- Are caregiver needs identified by a healthcare professional?
- Are caregivers aware of the available resources?
- Are provisions of the available resources?

Future Recommendations

- Compare caregivers with previous healthcare experience to those without previous healthcare experience
- Identify why caregivers experience high levels of distress despite availability of resources
- Determine if current resources are beneficial to caregivers

Contribution to Clinical Practice

- Identifies available resources at Roswell Park for caregivers that providers and caregivers may not have been aware of
- Identifies available community resources general caregivers as well as those specific to cancer caregivers
- Encourage providers to question caregivers about their needs to build a stronger rapport with caregivers by providing resources and support

Roswell Park Caregiver Resources

- Adolescent and Young Adults Program
- Cancer Information Center
- Financial Assistance
- Genetic Counseling
- Legal Care
- Social Worker and Support Groups
- Nutrition
- Patient Advocate Program
- Palliative Care Program
- Rehabilitation
- Spiritual Care
- Volunteer Desk
- Bladder Cancer Support Group
- Breast Cancer Support Group
- General Survivor and Caregiver Support Group
- Lung Cancer Support Group
- Lymphoma, Leukemia, and Hodgkin’s Disease Support Group
- Lung Cancer and Lung Cancer Caregiver Group
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<th>Roswell Park Caregiver Resources Continued</th>
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<td>• Melanoma Support Group</td>
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<td>• Multiple Myeloma Support Group</td>
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<td>• Ovarian Support Group</td>
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<td>• Transplant/Cellular Therapy Patients/Support Group</td>
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<td>• Young Breast Cancer Support Group</td>
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Strengths and Limitations

Strengths
- Mixed-methods study design
- PI is employed at Roswell Park, and is familiar with Bone Marrow Transplant and Leukemia patients. PI was able to fully understand what caregivers were discussing and ask appropriate questions when necessary.

Limitations
- Small sample size
- Mostly Bone Marrow Transplant caregivers and providers
- Participants may have been less willing to fully contribute to focus group discussions out of feelings of guilt or embarrassment.

References


References