# Health Perceptions of Cancer Caregivers Harvesting at an Urban Garden

Thesis

Presented in Partial Fulfillment of the Requirements for the Degree of Master of Science in the Graduate School of The Ohio State University

By

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Graduate Program in Allied Medicine

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2019

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Abstract

Treatment of cancer results in both acute and late effects, the burden of which is often shared with caregivers. These caregivers are typically uncompensated, and the care they provide involves significant amounts of time and energy, and may be physically, emotionally, socially, and/or financially challenging. Thus, the complex and demanding role of cancer caregiving is often associated with psychosocial, behavioral, and physiological stressors. A paucity of data exists regarding this understudied and overlooked population, and foundational work is warranted to fully characterize the unique experiences and perceptions of these individuals. The primary objective of this study was to identify perceived outcomes and changes in quality of life among cancer caregivers harvesting at an urban garden. Cancer caregivers who actively harvested at an urban garden during the 2018 growing season were recruited via secure email. Participants completed a self-administered demographics survey. Semi-structured phone interviews were conducted using an open-ended question guide to elicit the perceptions of caregivers. Participant responses were audio recorded, transcribed verbatim, and analyzed using conventional content analysis in NVivo qualitative analysis software to identify overarching themes and subthemes. Of the nine caregivers who completed interviews, four (44%) were male and five (56%) were female with 78% spouses (n=7) of cancer survivors. Caregivers harvested an average of nine times throughout the June through September harvesting season. Caregiver responses resulted in identification of four overarching themes: (1) improved physical and mental health, (2) improved dietary patterns, (3) improved social support, and (4) maintenance of positive behaviors. Caregivers reported improved quality time with their survivor,

benefits of consistent access to fresh garden produce, value in supplemental resources (e.g., recipes and education) from dietetics student volunteers, specific benefits related to enhanced social interactions, and enhanced support for maintaining behaviors they had previously tried to implement for themselves and their survivors. These data indicate harvesting at an urban community garden provided these individuals with support to overcome challenges commonly associated with cancer caregiving. Moreover, harvesting served as a mechanism by which this high-risk cohort could maintain lifestyle patterns commonly recommended in this population but often considered challenging to sustain. These results will inform future targeted interventions designed to decrease caregiving burden, encourage effective coping strategies, and improve physical and mental health, marital-family relationships, and social well-being in this high-risk cohort.

Acknowledgements

I would like to sincerely thank my advisor, Dr. Colleen Spees, for encouraging and supporting me throughout my research project. Your research and the Garden of Hope are what initially sparked my interest in attending The Ohio State University and I am very grateful to now be involved in your lab and learning from someone who is so passionate about her research. I would also like to thank Ashlea Braun who provided thoughtful guidance and feedback throughout my project.

I would also like to thank Dr. Chris Taylor and Annie Trance for serving as committee members and providing guidance and expertise to my project. Lastly, I would like to thank my family for encouraging me and continuously supporting my education.

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# Chapter 1: Introduction

## Background of the Problem

The American Cancer Society (ACS) defines a cancer survivor as "any person with a history of cancer, from the time of diagnosis through the remainder of their life."[1] As of January 2019, it is estimated that there are 16.9 million cancer survivors living in the United States, about 5% of the population. In the next 10 years, the number of cancer survivors is projected to increase by 29%.[2] The ACS recognizes three stages of cancer survivorship: time from diagnosis through the end of initial treatment, the transition from treatment to extended survival, and long-term survival. Advances in early detection and treatments have led to an overall decrease in mortality over the past two decades, leading to more long-term survivorship: 67% of survivors in 2019 have survived five or more years after diagnosis.[3] Although many are achieving long-term survivorship, cancer survivors are often living with the long-term late effects of treatments and psychological concerns such as fear of recurrence.[1]

The acute and long-term effects of cancer carry significant burden, which survivors often share with unpaid, informal caregivers.[4] These cancer caregivers are typically family members (88%) with most caring for a parent, spouse, or sibling.[4] As cancer treatments are increasingly delivered at outpatient care facilities, informal caregivers are needed to pick up where the health care team leaves off between and after treatments.[1] These responsibilities include, but are not limited to, accompanying cancer survivors to appointments, communicating with providers, assisting in decision making, providing medical care at home, providing emotional support, and assisting with activities of daily living.[4,5]

The experience of cancer caregiving is demanding and often accompanied by negative psychosocial, behavioral, and physiological effects on their daily lives and health.[6] The average time per week spent caregiving for a cancer survivor is 33 hours, with some caregivers continuing to hold paid employment in addition to their informal caregiving roles.[4] Because caregivers dedicate extensive time and energy to the care of their survivor, their own health can become compromised. Common health problems associated with caregiving include stress, depression, fatigue, headaches, and weight fluctuations.[7] Caregiving can also negatively impact the health behaviors of those taking on this new role, including physical activity and dietary patterns.[4,8,9]

Research suggests interventions targeting cancer caregivers may improve the health and overall experience of these individuals.[10] Caregiving interventions are often combined dyadic programs with the cancer survivor, and traditionally focus on the outcomes of the survivor. However, targeted intervention programs for caregivers alone have shown to decrease caregiving burden, encourage effective coping strategies, and improve self-efficacy, physical functioning, marital-family relationships, and social functioning.[11] Caregivers and survivors have an interdependent relationship, with a growing body of literature demonstrating changes in health of one individual impacts the health of the other.[12–14]

**Statement of the Problem**

Cancer caregiving is a demanding role which can result in negative physical and mental health outcomes.[15] The duties that accompany caregiving disrupt the routine and daily lives of these individuals, leading to negative impacts on psychosocial health and health behaviors like physical activity and diet.[16–18] Therefore, targeted interventions

addressing lifestyle behaviors can improve the health outcomes of caregivers. Traditional interventions for cancer caregivers specifically include education and support groups, but few target modifiable lifestyle behaviors.[14] This focus demonstrates strong potential, given the cancer survivor/caregiver dyad is a closely intertwined relationship.[12,19] Indeed, evidence suggests the poor health of one person (i.e., the caregiver) may adversely affect the partner's (i.e., the survivor's) health outcomes, creating a spillover effect.[12] Therefore targeted interventions for caregivers may not only improve physical and mental health outcomes of the caregiver, but the cancer survivor, as well.[12]

Urban community gardening and harvesting is one approach to encouraging healthy lifestyle behaviors in cancer caregivers. Harvesting at community gardens has been shown to improve fruit and vegetable intake, physical activity levels, and mental health, and foster a sense of community and increased social interactions.[20–25] Existing data documenting the challenges commonly faced by cancer caregivers point to a strong potential for these interventions in this high-risk population. Considering the range of health benefits and increased social connectedness resulting from participation in community gardens, foundational work is needed to understand the role urban gardens may play as a novel intervention to improve the health and quality of life of cancer caregivers.

James*Care* for *Life* (JCFL) is an extension of Ohio State University's Comprehensive Cancer Center (OSU-CCC). This department provides a variety of programs and resources for cancer survivors and caregivers throughout their cancer journey. James*Care* for *Life* offers programs focusing on exercise, education,

expressive arts, mind and body, families, and nutrition. These programs are provided free of charge and can be accessed by survivors and caregivers starting at the time of diagnosis. The nutrition programs focus on the American Institute for Cancer Research (AICR) evidence-based dietary guidelines for cancer prevention and survivorship, which advocate for the adoption of a primarily plant-based diet for optimal health.[26] The largest nutrition program offered by JCFL is the Garden of Hope (GOH), a community garden located on The Ohio State University's Waterman Farm. This two-acre garden provides a plentiful harvest of various fresh vegetables, fruits, and herbs for cancer survivors and their caregivers. In order to participate, individuals attend an orientation prior to the harvesting season which includes relevant education. This includes a Registered Dietitian-facilitated session covering the benefits of a plant-based diet and safe food handling, while the garden manager teaches optimal harvesting techniques. Each survivor and caregiver receive a reusable bag for harvesting, and after completion of orientation, they are allowed to harvest at the garden up to three times a week. At each harvest session, dietetic student interns are available to offer education on the nutritional benefits and the produce, and JCFL volunteers are available to assist with harvesting as needed.

There is currently a dearth of evidence examining the impact of urban harvesting on cancer caregivers' physical and mental health perceptions and overall quality of life. The GOH is one of few cancer caregiver gardens linked directly to a Comprehensive Cancer Center in the nation. This setting is an ideal and unique environment to examine the relationship between urban harvesting and health of cancer caregivers. Thus, a

better understanding of the impact of the GOH on cancer caregivers could lead to improved interventions for this understudied and vulnerable population.

**Purpose of the Study**

The purpose of this study was to identify perceived outcomes and changes in quality of life among cancer caregivers harvesting at an urban community garden. The impact of participation in the GOH Program, during one harvesting season, will be assessed to inform future interventions among cancer survivors and caregivers for program improvement. The objectives of the study were as follows:

**Objectives of the Study**

- To identify perceived outcomes and changes in quality of life among cancer caregivers harvesting at an urban garden.
- To determine if urban harvesting led to changes in perceived physical health in cancer caregivers.
- To determine if urban harvesting led to behavior changes in cancer caregivers.
- To understand the perceptions of social support among cancer caregivers harvesting at an urban garden.
- To describe the perceived mental health impact of cancer caregivers harvesting at an urban garden.

**Hypothesis**

Harvesting at an urban garden improves the perceptions of health and quality of life in cancer caregivers.

## Chapter 2: Literature Review

The American Cancer Society (ACS) defines a cancer survivor as "any person with a history of cancer, from the time of diagnosis through the remainder of their life."[1] As of January 2019, there were an estimated 16.9 million cancer survivors living in the United States, about 5% of the population. In the next 10 years, the number of cancer survivors is projected to increase by 29%.[2] The ACS recognizes three stages of cancer survivorship: time from diagnosis through the end of initial treatment, the transition from treatment to extended survival, and long-term survival. Improvements in health behaviors and advances in early detection and treatments has led to an overall decrease in mortality over the past two decades.[3] Long-term survivorship is becoming more common as 67% of survivors in 2019 have survived five or more years after diagnosis. Although many are achieving long-term survivorship, cancer survivors are often living with the long-term effects of treatments and psychological concerns such as fear of recurrence.[1] Because of the acute and long-term effects of cancer, the burden of cancer is often shared with informal caregivers.[4] Cancer caregivers are defined as unpaid, informal caretakers of a relative or friend diagnosed with cancer.[27] These cancer caregivers are often family members (88%) with most caring for a parent, spouse or sibling. As cancer treatments are now commonly delivered in the outpatient setting, informal caregivers are needed to pick up where the health care team leaves off between and after treatments.[1] Due to the debilitating nature of this chronic illness, many cancer survivors must rely on family and friends to assist with care throughout the many stages of cancer diagnosis, treatment, and recovery.[4]

## Role of Cancer Caregivers

Caregivers often take on a variety of roles to meet the emotional and physical demands of the individual facing cancer throughout the trajectory of treatment and survivorship.[5] These roles can vary depending on the type of cancer, disease progression, and treatment regimen of the cancer survivor. Caregivers perform various roles including accompanying cancer survivors to appointments, communicating with providers, assisting in decision making, providing medical care at home, providing emotional support, and assisting with activities of daily living.[4,5] The National Alliance on Caregiving published a research report in 2016 describing current cancer caregiving experiences. This report found caregivers provide assistance with an average of 2.4 out of 6 activities of daily living (ADL), activities related to personal care.[4] These ADLs include getting in and out of beds and chairs, getting to and from the toilet, getting dressed, feeding, bathing, and dealing with incontinence. This is higher compared to the average of 1.6 ADLs reported by non-cancer caregivers. In addition, cancer caregivers provide assistance with 4.6 out of 7 instrumental activities of daily living (IADL). These include: transportation, housework, grocery shopping, meal preparation, giving medicines, managing finances, and arranging outside services. Cancer caregivers often take on medical and nursing tasks they are not specifically trained for: 43% of cancer caregivers reported providing complex nursing tasks without preparation, and 17% reported these tasks being very difficult.[4] Lastly, advocacy is an additional role of a caregiver, as these individuals often communicate with health care professionals and agencies about the care of their loved one.[4]

## Caregiver Burden

Cancer caregivers often experience physical, emotional, and financial strain over the time spent caring for a loved one. Compared to other medical conditions, cancer caregivers experience a higher burden of care.[4] Burden of care is often quantified in the literature using total number of hours providing care, the number of ADLs provided, and the number of IADLs provided.[28] Compared to 38% of all caregivers, 62% of cancer caregivers experience a high burden of care, meaning their caregiving role is more time and energy-demanding than non-cancer caregivers. On average, cancer caregivers spend 32.9 hours a week providing care, while non-cancer caregivers provide 23.9 hours of care a week.[4] Compared with other common caregiver groups (dementia, diabetes, and frail older adults), cancer caregivers have the shortest duration of care, but the intensity of care is more demanding.[16] Because of this, cancer caregiving is described as intense and episodic, requiring the most care after diagnosis and surgeries.[4,16] Research shows caregiving burden is also associated with the age of the survivor and the employment status of caregiver, as older adults need more functional care while working caregivers experience more stress balancing competing demands.[29]

## Psychosocial Impacts of Caregiving

The demanding nature of cancer caregiving can lead to changes in psychosocial health, which can include factors related to mental, emotional, social, and spiritual health, as defined by The National Cancer Institute.[30] Existing evidence suggests a cancer diagnosis has a more profound effect on the mental health of the caregiver than that of the patient because of the many stresses associated with caregiving.[31–33] There are many factors associated with caregiving that increase stress: adjusting work,

needing to change personal plans, and feeling completely overwhelmed.[34] Indeed, half of cancer caregivers report experiencing high levels of emotional stress.[4] Changes in psychosocial health often begin at diagnosis as the caregivers are usually surprised and in shock with the news of a cancer diagnosis. From this point on, caregivers experience an emotional journey with feelings of overwhelm, exhaustion, disconnect, and loneliness.[17] The surprise of a cancer diagnosis is often accompanied by a perceived lack of preparedness for their new role, and associated feelings of fatigue, confusion, and mood disturbance.[18] A study amongst lung cancer caregivers reported decreased time for social activities, decreased levels of energy, decreased emotional wellbeing, and a decreased ability to cope with stress.[33]

**Health Behaviors of Cancer Caregivers**

Evidence on the health behaviors of cancer caregivers is limited and has conflicting results.[35] Some research suggests health behaviors are not impacted by the burden of cancer caregiving,[36] while other studies suggests caregiving can indeed be a hindrance to health behavior.[17,34] This impact on health behavior may be related to the time dedicated to cancer caregiving roles, resulting in less time for caregivers to dedicate to their own health, including engaging in physical activity and maintenance of a healthy dietary pattern.[17] A study analyzing the health behaviors of caregivers of patients with advanced cancer found that less than 50% of caregivers met the physical activity guidelines of 150 minutes of moderate intensity activity per week. Of these caregivers, 60% indicated their caregiving responsibilities did not interfere with physical activity.[37] This study also revealed 40% of caregivers reported their caregiver responsibilities interfered with their ability to eat a healthy diet.[37] Similarly, a study

among lung cancer caregivers revealed that 5% of caregivers ate at least five fruits and vegetables per day while 16% performed at least 30 minutes of physical activity five times a week.[38] Researchers surveying ovarian cancer caregivers found that 54% of caregivers did not meet physical activity recommendations and 71% were overweight or obese.[8] Of these caregivers, 42% reported their physical activity levels had decreased since the cancer diagnosis of their loved one. The participants linked their negative health behavior changes to the emotional and physical demands related to caregiving which interrupted their daily routine.[8]

Conflicting with evidence that caregiving has a negative impact on health behaviors, some evidence suggests that a cancer diagnosis can be a "teachable moment" for caregivers and encourage healthy behavior change.[39] A teachable moment is described as a "naturally occurring life transitions or health events thought to motivate individuals to spontaneously adopt risk-reducing health behaviors."[40] Cancer survivors are often looking for ways to reduce their risk for cancer recurrence and improve the quality and length of their life.[41] Similarly, family and friends of survivors are motivated to improve their own health to reduce risk of developing cancer and to support the health behavior changes their survivor is implementing.[42] The timing of a teachable moment, often soon after diagnosis, is when health behavior interventions have potential for long-term success for both survivors and caregivers.[39,41] A 2007 study showed cancer survivors and their family made more positive health behavior changes, including increased physical activity, smoking cessation, increased fruit/vegetable intake, and decreased eating out.[39] Similarly, a study among women with a family member recently diagnosed with breast cancer reported improving health behaviors,

including adopting a healthier diet, increasing physical activity, and limiting alcohol and tobacco use in response to the recent diagnosis.[43] Although these studies did not specify caregivers, it suggests that the family and friends closest to cancer survivors may use a cancer diagnosis to initiate behavior change for adaptation of a healthier lifestyle in an effort to support their cancer survivor or lower their own risks for cancer.[39,43] With 88% of caregivers being family members, these data may relate to caregivers as well.[4]

**Cancer Caregiver Interventions**

A 2017 review of family cancer caregiver intervention trials found 50 randomized control trials among cancer caregivers from 2010-2016.[44] Of these trials, three categories of interventions emerged: (1) patient caregiving content, information, and skills related to caregiving tasks; (2) marital/family care, information, and skills related to coping and relationships; and (3) caregiver self-care, information, and skills related to caregivers own management of stress related to caregiving. Most common were interventions focusing on symptom management and physical care related to patient caregiving, while the second most common were caregiver self-care interventions, including health and emotional self-care, social support, and accessing resources.[44]

With evidence showing the impact of cancer caregiving on health and quality of life, a growing body of literature is focusing on caregiver interventions to reduce the associated burden of this role while improving health outcomes. A 2012 study explored the perceptions of cancer caregivers participating in an exercise and nutrition program alongside their cancer survivor.[45] In this study, participants completed Strong Survivors, a 12-week program focusing on basic nutrition and exercise to help manage the

physical and psychosocial issues survivors and caregivers face. The participants were assigned personal trainers to meet with twice per week for personalized fitness programs. Data from focus groups demonstrated several recurring themes, including increased quality time and support among survivors and caregivers, improved strength and endurance, increased energy, improved psychosocial outcomes, and better social support.[45] Similarly, survivors and caregivers who participated in an eight week exercise and nutrition program (ENRICH: Exercise and Nutrition Routine Improving Cancer Health) increased daily steps and vegetable intake while decreasing their body mass index (BMI).[46]

A more recent 2017 study explored the effects of a structured exercise program in cancer caregivers.[47] This Canadian study implemented a 12-week exercise program for cancer caregivers, consisting of group fitness classes and independent exercise sessions that met the Canadian physical activity recommendations. This program also included educational sessions over healthy behaviors and stress management.[47] Participating in the exercise intervention improved levels of physical activity and aerobic fitness in caregivers. This study also measured self-reported quality of life: caregivers in the intervention and control group did not have differences in the physical health component of the quality of life score. However, caregivers in the intervention group had improved mental health outcomes within quality of life scores compared to the control group.[47] Qualitative data from caregiver interviews indicated participants felt the intervention led to a positive shift in their lifestyle. Prior to the study, caregivers described a “downward spiral” from being overwhelmed, experiencing negative lifestyle changes, and physical and emotional health declines. After the intervention, caregivers

described an “upward spiral” from taking control of their health, gaining physical and emotional strength, and experiencing positivity and camaraderie. Overall, the participants credited better physical and emotional health to the exercise program.[48]

Lapid et al. assessed the long-term benefits of a quality of life intervention among cancer caregivers and found targeted interventions can improve cancer caregiver quality of life.[10] This study used six multidisciplinary information sessions over four weeks, consisting of physical therapy, education, spirituality, stress management, and social needs sessions. The control group received usual care without the interdisciplinary sessions. Caregivers experienced improvements in spiritual well-being, vigor/activity, fatigue, and adaptation components of quality of life scores, while the control group scores decreased immediately post-intervention. This study also examined the long-term effects at 27 and 52 weeks post intervention, with findings indicating the intervention group sustained their improvements in quality of life as compared to controls.[10]

**Garden and Harvesting Interventions**

Garden-based interventions among a variety of populations have proven successful in increasing fruit and vegetable intake, physical activity levels, and quality of life.[20–25,48–50] Youth and school community gardens are being utilized to educate children and teens on healthy eating habits, improve access to a variety of vegetables, reduce childhood obesity, and encourage higher fruit and vegetable intakes.[49–51] Urban gardens are also being utilized as mechanisms to improve access to fresh produce and encourage healthy eating habits. Urban gardens can be sponsored by local organizations and often target low-resource or high-risk populations who do not have

regular access to produce. These gardens offer produce for free or at a low cost with garden participation.[51,52] Despite documented health benefits, no gardening or harvesting interventions have specifically targeted cancer caregivers.

Community gardens not only lead to positive health benefits among participants, but social benefits as well. Community gardens foster new social interactions within the community while strengthening existing relationships of participants through harvesting together.[52,53] Carney et al. found families participating in a community garden had an increased sense of togetherness and spent more quality time together as a result of gardening.[53] A study of community gardens in New York found community gardens increased the sense of community and enhanced social networking.[52] Similarly, a study among community gardeners in Baltimore revealed gardeners associated community gardens with building social bonds, breaking down social barriers, and connecting with a larger community. The community gardens facilitated social interactions and feelings of shared responsibility among participants.[23]

**Gardening and Harvesting for Cancer Survivors**

Health outcomes have been measured in garden-based interventions among cancer survivors, but not in cancer caregivers. A 2018 study paired breast cancer survivors with master gardeners to provide mentorship for a home vegetable garden.[54] The participants were given all of the supplies to create a garden at home, and the master gardeners communicated with participants bimonthly to provide mentorship for planting and maintenance. After completing the yearlong intervention, participants reported higher vegetable intakes, physical activity levels, and improved health-related

quality of life (HRQOL). Two years after the study, 86% of participants were still gardening.[54]

Health behaviors of cancer survivors participating in the GOH program have been studied, but behaviors of the caregivers participating have not.[22] A 2015 study exploring the health behaviors and perceptions of the survivors harvesting at an urban garden used focus groups to examine perceptions of the survivors harvesting. The results indicated survivors increased vegetable intake and adopted healthier cooking habits, had improved mental and physical health, and experienced enhanced community support.[24] A separate study at the GOH measured health biomarkers in a cohort of survivors after one harvest season. Cancer survivors showed improved health biomarkers such as fasting blood glucose, blood pressure, biomarkers of fruit and vegetable intake (e.g., skin carotenoids), and blood lipid levels.[22]

**Gardening and Mental Health**

Studies have shown gardening can improve mental health by offering a therapeutic environment to promote stress relief. A 2010 study examined the impact of gardening and reading as a recovery from induced stress.[55] The results demonstrated cortisol levels dropped significantly after the participants completed the garden activity, with improvements greater than that observed in the reading group. This therapeutic effect was credited to the combination of physical activity and connection with nature experienced while gardening.[55] A later study showed a 12-week therapeutic gardening intervention reduced depression and increased social activity and group cohesiveness among participants.[56] Additional work examining the health benefits of allotment gardening (when community members rent a small plot of land outside of their home to

grow food) found gardeners, compared to non-gardeners, had improved self esteem and mood after completing a gardening session. The gardeners further reported enjoyment from being outside, a sense of achievement, and perceiving an opportunity for restoration and stress relief.[57]

**Need for Caregiver Interventions**

With more evidence showing the impact cancer caregiving has on physical and mental health, targeted caregiver interventions are becoming increasingly valued. In 2016, The National Cancer Institute and the National Institute for Nursing Research published recommendations for addressing the challenges of cancer caregiving.[14] This report identifies the burdens and challenges of caregiving, as well as the three types of cancer caregiving interventions: patient, caregiver, and patient/caregiver dyads. The recommendations include expanding research into the experience of cancer caregiving, defining outcomes of interest in intervention studies, national tracking of caregivers and their level of burden, collaborations among agencies, national conferences, and modifying healthcare to be family-oriented rather than patient-focused.[14]

Research suggests family-based cancer prevention programs can improve the health behaviors and relationships of survivors and caregivers.[42] In a study of lung cancer survivors and their families, participants reported a readiness to make lifestyle changes together through a health promotion program. Survivors preferred an intervention integrating exercise and stress management, while family members expressed interest in a program including diet, exercise, and stress management.[38] Similarly, a 2015 study asked cancer caregivers what they needed the most help with or information on regarding their caregiver experience. The most requested assistance

was with managing emotional and physical stress, with 43% or caregivers saying this was their highest need.[4] With the evidence suggesting positive mental and physical health outcomes with community gardening, gardening may serve as a novel intervention to address the strains of caregiving and meet these documented needs.

**Semi-Structured Interviews**

Qualitative research gives insight to attitudes, beliefs, behaviors and motives of the target population.[58] This type of research allows for a greater depth of understanding, particularly of outcomes that are challenging to measure via traditional mechanisms, by evaluating emotional and contextual human responses.[59] Interviews are a commonly used form of qualitative data collection. Three categories of interviews exist: unstructured, semi-structured, and structured interviews. Unstructured interviews have a clear plan but do not have control over the interviewee's response. These interviews can take a great deal of time and go in many directions as the interviewer has limited control on the discussion. Structured interviews consist of a fixed question guide that is asked identically to all interviewees. These interviews are similar in provision to a survey being read out load, and are most commonly used in very large samples. Semi-structured interviews are a common type of interview as they utilize a set of predetermined open-ended questions while allowing for other questions to emerge from the dialogue between the interviewer and interviewee. These interviews are appropriate when interviewers want to understand a topic thoroughly and comprehend perceptions of events and experiences.[60,61]

The first step to preparing research questions for a semi-structured interview and determining the main research questions.[60] This guides the researcher in developing

the question guide. Harrel et al. describes three types of questions that can be used when designing a question guide: descriptive, structural, and contrast. Descriptive questions ask the interviewees to describe their experiences and may provide insights for follow up questions the researcher may not have considered. These questions can often result in a narrative which can result in a lengthy response from the interviewee. Structural questions allow the researcher to understand the relationship between factors, and can often result in a list. Contrast questions allow the researcher to understand what terms mean and differentiate between items the researcher has already obtained. Problem question styles may include double barreled questions, leading questions, double negative questions and vague questions. Using more neutral questions prevents biasing the interviewees responses.[60]

A key component of semi-structured interviews is the use of probes. Probes allow for clarification of responses and to elicit additional information to follow up on the initial response. Interviewers can use probes if they do not understand the response, or if they feel the interviewee has not shared everything they can. Probes can also help clarify the question to the interviewee so their response better answers the question. These probes encourage the interviewee to share as much information as possible in their own words, while delving into perceptions beyond superficial commentary.[61] Repeating the question, pausing, and echoing the response can all allow the interviewee to process the question and provide further details.[60]

Depending on the subject and specific research questions, semi-structured interviews can follow several different protocols. Four approaches exist for designing semi-structured interviews: funnel, inverted funnel, tunnel, and quintamensional. Funnel

protocols start with broad questions and narrow in to more focused questions, whereas inverted funnels start with narrow questions and lead to a broad discussion. The tunnel method uses an equal depth of questions throughout the interview. Lastly, the quintamensional method uses a five step process to measure awareness, attitudes and reasons, and intensities of these attitudes.[60]

**Semi-Structured Interviews in Urban Harvesting**

Limited studies have used rigorous mixed methods data collection techniques (e.g., semi-structured interviews) to measure perceptions in urban harvesters. A 2014 study in Baltimore used in-depth semi-structured interviews and focus groups to elicit perceptions of the benefits of community gardening experienced by individual gardeners and the community. This study first conducted semi-structured interviews with 17 gardeners using an interview guide, however also allowed participants to lead the conversation. Additionally, the researchers conducted two focus groups with a total of 11 participants. The in-depth, semi-structured interviews served to delve into individual gardening experiences while the focus groups assessed areas of consensus among community gardeners. These methods resulted in the identification of several benefits of community gardening. Specifically, the individual interviews revealed that gardening helped the individual to thrive physically, psychologically, and socially. The physical benefits included increased vegetable intake and physical activity through the act of gardening itself. The psychological benefits included inherent joy in gardening and a spiritual connectedness to nature. Socially, the gardeners credited benefits to breaking down social barriers and creating social bonds.[23]

# Chapter 3: Methods

The purpose of this study was to identify perceived outcomes and changes in quality of life among cancer caregivers harvesting at an urban community garden. The impact of harvesting produce during one season at the GOH will be assessed to inform future interventions among cancer survivors and caregivers for program improvement. The objectives of the study were as follows:

- To identify outcomes and perceptions of quality of life improvements among cancer caregivers harvesting at an urban garden.
- To determine if urban harvesting led to changes in perceived physical health in cancer caregivers.
- To determine if urban harvesting led to behavior changes in cancer caregivers.
- To understand the perceptions of social support among cancer caregivers harvesting at an urban garden.
- To describe the perceived emotional response of cancer caregivers harvesting at an urban garden.

## Research Design

In order to meet the predetermined objectives, this study employed a mixed method research design to capture a rich description of the unique perceptions and experiences of cancer caregivers harvesting at the GOH. After IRB approval, JCFL staff sent a secure recruitment email to caregivers who harvested at the GOH three or more times during the 2018 harvest season. These individuals were identified using harvest attendance records maintained by JCFL staff over the course of the harvesting season, and this selection method served to ensure recruitment of individuals who had adequate

exposure to the GOH for reflection of their experiences. Recruitment emails were sent one month after the conclusion of the harvest season to allow time for reflection on the harvest season and identification of maintenance of behaviors. All individuals contacted were provided a description of the study, the risks and benefits of participating, assurance that all information would be kept confidential, and confirmed there was no penalty for choosing not to participate. Caregivers who expressed interest in participation were provided a secure link to complete a quantitative self-administered questionnaire to collect basic demographic and caregiver specific history. Once complete, caregivers emailed the research team to schedule a phone interview.

Phone interviews were completed using a qualitative semi-structured interview format to elicit the perceptions of participating caregivers using a predetermined questioning route. Qualitative research methods were appropriate to use for the semi-structured interviews in order to understand the unique perceptions and experiences of each individual cancer caregivers harvesting at the GOH. Utilizing a questioning route of open-ended and follow-up questions for individual interviews, the benefits of caregivers participating in a four month, June through September, harvest season were determined. The interviews were audio recorded and transcribed verbatim prior to being imported in Nvivo (Nvivo Plus version 12.0, QRS International, Australia, 2018) for coding and analysis. The results from the interviews will be used to inform future intervention for cancer caregivers.

**Questioning Route**

1. Describe your overall experience at the Garden of Hope this past summer.
    - Probe: How was the Garden of Hope a positive experience?

2. How has harvesting at the Garden of Hope impacted your overall health?
    - Probe: How has harvesting impacted your physical health?
    - Probe: How has harvesting impacted your mental health?
3. What types of changes, if any, did you make to your diet or lifestyle as a result of participating in the Garden of Hope program?
    - Probe: Is there anything you still do now?
4. How has harvesting at the Garden of Hope impacted your relationships?
    - Probe: How has harvesting at the Garden of Hope impacted your relationships with your cancer survivor you care for?
    - Probe: Did harvesting at the garden impact your routine together?
    - Probe: Did you create any new relationships at the Garden of Hope?
5. Overall, what did you feel was the most beneficial piece of the Garden of Hope program?

**Question Route Development**

Questions for the semi-structured interview route were developed by a team of researchers from The Ohio State University School of Health and Rehabilitation Sciences, Division of Medical Dietetics. The interview route questions were designed to reflect the study objectives while also allowing participants to describe their experiences by responding to non-leading, open-ended questions in a funnel protocol.[58,60] The question route utilized two types of questions, descriptive and structural. The descriptive questions were designed to elicit a narrative of experiences, while the structural questions allowed allow participants to list or identify experiences. The funnel protocol was used to start the participants reflecting on their overall experiences harvesting, then

narrowing into specific aspects and outcomes of harvesting.

## Data Collection

### *Questionnaire*

Upon identification via email and prior to completing a phone interview, participants completed an anonymous self-administered questionnaire via Qualtrics Survey Software. Demographics questions were adapted from the Behavioral Risk Factor Surveillance System (BRFSS), and additional caregiver-specific questions were included.[62] Caregiver-specific questions were designed to provide descriptive data regarding the participants' caregiving history and experiences in the GOH (see Appendix).

### *Semi-Structured Interviews*

All semi-structured interviews and related data collection was completed by the primary author. This researcher was trained by a qualitative research expert and mentored throughout the process. The primary author called each caregiver at the scheduled interview time, at which point participants were reminded of the purpose of the study and were explained the structure of the interview. Next, the participants were asked if they agreed to have their interview recorded. The researcher followed the semi-structured question route and used reflective listening and probing to elicit depth in participant responses. All interviews were audio recorded using a digital recording device and the recordings were uploaded to a secure database and then transcribed verbatim by the primary author. All identifying information was removed. At the completion of the interview, the researcher thanked the participant for their time and asked for an address for delivery of a $10 gift card. The gift card was mailed to participants homes and the research team required a confirmation email when the caregivers received their gift card. Interviews were

conducted until saturation was reached. Thematic saturation was determined when no new themes were emerging from the interviews.[63] After nine interviews were completed, the research team concluded that no new themes were emerging and further interviews did not need to be conducted.

**Data Analysis**

Data from self-administered quantitative questionnaires were analyzed for descriptive statistics, including calculations of means and standard deviations. The audio transcripts were analyzed to identify themes and patterns through inductive processes of conventional content analysis and the constant comparison method.[58,64] In addition to the primary author who conducted the interviews, one additional researcher reviewed the transcripts to evaluate themes and establish codes. The transcripts were first reviewed individually to identify overarching themes, after which the researchers came together to compare themes and discuss initial codes for the codebook. Accordingly, the primary author created an initial codebook consisting of codes, definitions of codes, and examples. The researchers met again to review the codebook and discuss any changes before finalizing. The final codebook consisted of six individual codes that were agreed upon by both researchers. As a calibration test, the researchers individually coded four interview transcripts and met for comparison. The researchers discussed every code and compared and calculated agreements and disagreements. Any coding discrepancies were discussed and the research team came to a consensus.

To calculate interrater reliability, the two researchers individually coded the fifth transcript in Nvivo. The transcripts were compared through the Nvivo comparison query to calculate the kappa statistic. The results showed that the coders had a 0.81 kappa statistic,

exhibiting almost perfect agreement.[65,66] Additionally, the percent agreement was calculated by dividing the total number of agreements by the total number of codes. The result was an 89% agreement. Once this strong interrater reliability was established, the primary author independently coded the remaining four transcripts. Once all transcripts had been coded by hand, they were coded using the Nvivo software to evaluate overarching themes and identify subthemes. Subthemes were determined by identifying common ideas within each theme. Subthemes that were present in over half of the transcripts were given a subcode to track the subthemes throughout the transcripts.

# Chapter 4: Results and Discussion

## Results

Nine caregivers participated in semi-structured interviews. Table 4.1 details the characteristics and caregiving history of the participants. All of the participants were Caucasian (100%), five (56%) were female and four (44%) were male. The majority of the participants (78%) were spouses of the cancer survivors. Over half (56%) of the survivors were still in active treatment. The average age of the caregivers was 65.4 years (SD 7.1), while the cohort ages ranged from 54-75 years of age. Over half (56%) of the participants had harvested at the GOH for one year, the others had participated in two seasons of harvest. The average years of cancer caregiving was 4.3 years (SD 3.6), and the range included 1-12 years caregiving. The majority of participants (67%) also participated in a gardening or nutrition class through JCFL during the harvest season.

Four overarching themes emerged from the interviews: (1) Improved dietary patterns, (2) improved perceptions of mental and physical health, (3) enhanced social support, and (4) maintenance of positive behaviors (Figure 4.1). Summary data of themes and subthemes along with illustrative quotes are provided in Table 4.2.

| Participant Characteristics (N=9) | | % (n) |
|---|---|---|
| **Age (average years ± SD)** | | 65.4 ± 7.1 |
| **Sex** | Male | 44% (n=4) |
| | Female | 56% (n=5) |
| **Race / Ethnicity** | White / Caucasian | 100% (n=9) |
| **Relation to Cancer Survivor** | Spouse | 78% (n=7) |
| | Friend | 11% (n=1) |
| | Other Family (Child) | 11% (n=1) |
| **Survivor Caregiving for in active treatment?** | Yes | 56% (n=5) |
| | No | 44% (n=4) |
| **First or second year at the GOH?** | First | 56% (n=5) |
| | Second | 44% (n=4) |
| **Years providing care for cancer survivor (average years ± SD)** | | 4.3 ± 3.6 |
| **Years providing care for cancer survivor** | 1-3 years | 56% (n=5) |
| | 4-6 years | 22% (n=2) |
| | 7-10 years | 11% (n=1) |
| | 11+ years | 11% (n=1) |
| **Participation in other gardening or nutrition programs** | Yes | 67% (n=6) |
| | No | 33% (n=3) |
| **Specific programs** | Container Gardening | 11% (n=1) |
| | How to Start a Home Vegetable Garden | 22% (n=2) |
| | Maintaining Your Home Vegetable Garden | 22% (n=2) |
| | Healthy Eating for the Cancer Survivor | 22% (n=2) |
| | Living a Plant Based Lifestyle | 22% (n=2) |

Table 4.1 Participant Demographics and Characteristics

Data presented as percentages or means and standard deviations (SD) when applicable.
GOH: Garden of Hope

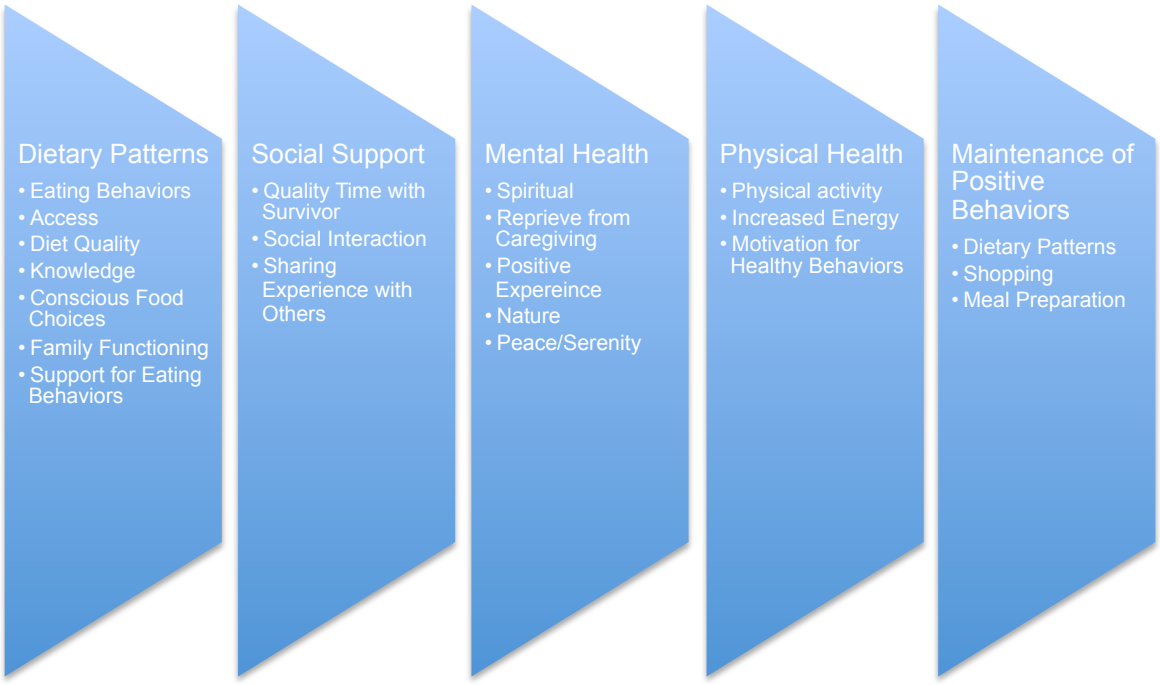


Figure 4.1 Summary of Overarching Themes and Subthemes

Description of themes identified from analysis of semi-structured interview transcripts, including descriptions and examples of each.

| Themes | Participant Quotes Supporting Themes |
|---|---|
| *Improved Mental Health* | |
| Spiritual | P7: Whoever thought you could get away from, here you are in the middle of the city. Here you are at the garden, and it's so serene and so beautiful. And it's pretty quiet. It's almost like a walk in the park, just to get away from the news, the bombardment of traffic and horns and it's not only does it feed your mind, soul, your body. It does all of those things. |
| Reprieve from Caregiving | P9: Just being able to get out, I mean from the caregiver side, is a little bit of a reprieve too. To go outside and get some fresh air and do something beyond just taking care of things at home and going to medical appointments and that type of thing. I guess, uplifting as a caregiver |
| Positive Experience | P8: When [my spouse] is in the hospital I'm there with her all the time. And this was a different kind of experience which was very positive. The other one is a positive experience because everyone is wonderful but it's different situation. It's painful.<br><br>P2: Obviously the food part was very great in coming to get free food and new things, getting to try that out. But it was more than that I think. I liked I feel like the mental health part was probably the biggest benefit. |
| Nature | P5: You know, you get something out of putting your hands in the dirt, helping other people and you're helping yourself as well.<br><br>P6: Just being out there, meeting the people, getting out in the sunshine, or the rain. Yea, I'm sure it was good being outside it helps for the mental health. |

Continued

Table 4.2 Interview Data- Illustrative Quotes

Table 4.2 continued

| | |
|---|---|
| *Improved Physical Health* | |
| Physical Activity | P9: I think it was good for me to get out and move around. You know it just, building my confidence that I can do that and do more of that at home and be outside more at home.<br><br>P4: It's just different than, say, being in a classroom seated. You are involved in physical activity, bending over, looking, walking down the aisles and things like that. |
| Motivation for Healthy Behaviors | P7: You just feel better. Because you feel better you just say "let's go out for a walk" or just continue exercise because you know you are putting good things in your body. We can say "let's go do this bike ride" |
| Increased Energy | P2: You just don't feel as bogged down. I don't know how to describe that scientifically, I think it just does make you feel a little bit better.<br><br>P7: You feel better. You don't just feel sluggish. |
| *Improved Dietary Patterns* | |
| Eating Behaviors | P1: It's more of a variety of salads that we enjoyed. Instead of just lettuce and carrots you know that kind.<br><br>P6: Eating the fresh picked stuff was certainly healthy and made us look for recipes that we might not have otherwise tried.<br><br>P9: Wherever I can I use fresh vegetables.<br>especially this summer, 2 veggies rather than meat and potatoes. Even to the point where I'd say at least 2<br>days a week we have meatless dinners. A lot more fish and veggies so that was a big shift cause (survivor) always had to have potatoes or noodles or something. |

Continued

Table 4.2 continued

| | |
|---|---|
| Access | P2: It certainly helps to go to the garden and get those green things.<br><br>P8: We got a lot of free vegetables |
| Diet Quality | P7: We are eating a lot more kale!<br><br>P1: Well we eat a lot better. You know vegetables and stuff, we have a salad every day |
| Knowledge | P4: It's learning about the produce and also the courage to try something that you haven't tried before. |
| Conscious Food Choices | P2: I know particularly about trying to eat like half your plate should be vegetables are greenery or fresh greenery or that kind of thing so we're kind of thinking more along those lines of trying to balance things a little bit better that way. |
| Support for Eating Behaviors | P3: We were already pretty conscious of enjoying more vegetables, but this gave us an extra little push. So that was good.<br><br>P6: We had consulted nutritionists on a couple of occasions during the course of [their] diagnosis and treatment, so we had learned about the plant based diet. But this was a little extra push in a way that made it more fun, because we get help to plan our menus according to the harvest. |
| I*mproved Social Support* | |

Continued

Table 4.2 continued

| | |
|---|---|
| Quality Time with Survivor | P1: We are spending more time together, quality time just cooking together. We're doing meal preparation together, shopping together.<br><br>P8: I thought that was a really neat experience going out there. It was fun and everyone was nice and it was just.. NAME and I would do it together and it was a great experience.<br><br>P8: It was a different kind of experience than going to the other part of the James and that was a very positive thing we could do together. And we both like it there. |
| Social Interaction | P7: I guess sometimes you feel that you are in this maybe by yourself. And then you almost have a built in support system when you go to the garden, you realize you are not the only person going through it. You don't even have to talk about it you just feel that support there.<br><br>P3: The students and the folks that helped out there were all very helpful and energetic and made it an enjoyable experience. |
| Sharing Experience with Others | P7: I just tell everybody what a wonderful, wonderful opportunity it is. It's not just for getting good, healthy, organic food but it's just, like I said before, it's food for the soul. I just think it's a wonderful, wonderful opportunity and experience for everybody. |
| *Maintenance of Positive Behaviors* | |
| Dietary Patterns | P9: We've done some where we've bought fresh vegetables and flash frozen them and kept them. We've got a big stash of green beans in my freezer for dinner. I think it's not just a summertime thing. It's knowing throughout the year we'll use and go to those sources.<br><br>P2: we are trying to make sure our meal is more balance on the plate kind of trying to do that vegetables. We are trying to work on that. Some meals are better than others. |

Continued

| | |
|---|---|
| Shopping | P8: We pretty much buy all of our fruits and vegetables from Whole Foods so you can get the stuff that was in the garden there, so we do.<br><br>P7: I continue to buy kale |
| Meal Preparation | P8: [my spouse] continues to look for new recipes and vegetables, we just eat a lot of that stuff. |

Table 4.2 Interview Data- Illustrative Quotes

Presentation of themes identified from qualitative analysis, including illustrative quotes which were identified during the analysis process and serve as key examples of each theme.

## Discussion

The purpose of this study was to identify perceived outcomes and changes in quality of life among cancer caregivers harvesting at an urban community garden. The results revealed four overarching themes related to the caregivers' perceptions: (1) improved dietary patterns, (2) improved mental and physical health, (3) improved social support, and (4) maintenance of positive behaviors. These themes encapsulate the key findings of the semi-structured interviews and align with the study objectives. The themes support the hypothesis of harvesting at the GOH improved the perceptions of health and quality of life among cancer caregivers. Overall, these findings are consistent with several garden studies in adult and cancer survivor populations documenting the positive health benefits associated with community gardens.[20–25,54,67] However, this study provides evidence for the benefits of harvesting in a social setting for the cancer caregiver population.

### Improvements in Dietary Patterns

Caregivers described the development of various new behaviors which served to positively shift their dietary patterns to align with the evidence-based guidelines promoting a primarily plant-based diet. The United States Department of Agriculture (USDA) defines dietary patterns as "the quantities, proportions, variety, or combination of different foods, drinks, and nutrients (when available) in diets, and the frequency with which they are habitually consumed."

#### *Increased Vegetable Consumption*

All caregivers reported increasing the overall amount vegetables they consume, most by over 50%, they also discussed increasing the variety of vegetables they consumed as a result of harvesting at the GOH:

> P3: …we've definitely been eating more vegetables than we used to. We've certainly always ate vegetables but we have increased our percentage of vegetable intake. And we are eating a few additional vegetables that we hadn't eaten before.

Others described shifting the proportions of the food groups in their dietary patterns by focusing on the MyPlate method (i.e., filling half of the plate with vegetables), as an approach to consistently increase the amount of vegetables consumed. The majority of caregivers stated the GOH not only improved the dietary patterns of the caregivers, but enabled the caregivers to better provide a more plant-based diet for their survivors.

*Variety/New Foods*

Caregivers reported enjoying learning about and trying new vegetables throughout the harvest season. The physical act of harvesting was a new and fun experience which made caregivers excited to try the new vegetables they harvested. Several caregivers mentioned specific vegetables, including Swiss chard and kohlrabi, as foods they had previously avoided, but are now incorporating into their diet because they harvested these vegetables at the GOH. Having access to multiple vegetables each week also added variety into caregivers' diets. Some caregivers mentioned their previous limited variety of vegetables, but that harvesting expanded the types of vegetables they consume:

P1: It's more of a variety of salads that we enjoyed. Instead of just lettuce and carrots you know that kind.

*Supplemental Resources*

Caregivers also mentioned the positive role of supplemental supportive resources as part of the GOH, including a recipe book as well as weekly emails, in encouraging incorporation of new vegetables. One caregiver described previous hesitancy experienced when buying vegetables in the grocery store:

P4: I want to try something but I don't have any recipes that I think it would use, or how much to cut or how to prepare it.

However, at the GOH they had the weekly recipes teaching them how to use the vegetables, and interactions with other caregivers and dietetics students to exchange recipes and ideas. Caregivers spent more time searching for recipes and seeking creative ways to use the vegetables they harvested from the GOH. This abundance of resources for how to prepare and use the vegetables in recipes led to more experimenting and increasing overall variety and volume of vegetables in caregivers' diets.

*Support for Dietary Behaviors*

Several caregivers described the GOH as supporting existing dietary patterns or as a reinforcement to align dietary patterns with those recommended by their survivors' health care team:

P6: We had consulted nutritionists on a couple of occasions during the course of (their) diagnosis and treatment, so we had learned about the plant-based diet.

But this was a little extra push in a way that made it more fun, because we get help to plan our menus according to the harvest.

Other caregivers mentioned following the MyPlate[68] guidelines and preparing meals that were balanced with half the plate filled with vegetables. One caregiver described using the vegetables they harvested to align their dietary patterns to match their survivors recommended diet:

P9: I knew that we had been successful in shifting that balance of veggies from starches and protein when we started doing, especially this summer, two veggies rather than meat and potatoes.

Most caregivers described these changes as being for both themselves as well as the survivor from whom they are providing care. Often, the conscious effort to make healthy diet changes was based off the dietary recommendations for the survivor:

P8: Well, you know, we mostly did it because of [my spouse's] situation. I think it really helps me to, I just think that, as far as our general health it really helps us out a lot.

The caregivers described learning about plant-based diets through a healthcare provider, and now trying to implement these dietary recommendations as part of their role as a caregiver. Having access to the fresh produce at the GOH enabled them to better provide the plant-based diet recommended to their survivor. Regarding incorporation of vegetables into in their survivors' diet, one caregiver said:

P9: It definitely made it easier for me to do that cause it was, you know a go-to place for me, close, successful, you can go get that.

This motivation to change aligns with the research on a cancer diagnosis creating a "teachable moment." Cancer patients and family members are often receptive to a family-based cancer prevention and health promotion program.[42]

Increases in vegetable intake while participating in a hands-on garden experience is well documented.[23,24,50,69] Specifically, the access to fresh produce at a garden combined with nutrition education has shown to improve adherence to a plant-based diet in children and adult populations.[20,24,53] Although this study did not measure physiological changes, some garden studies demonstrate that harvesting improved fasting blood glucose, HDL cholesterol, and skin carotenoid levels.[22] Other studies show that participating in gardening increased physical performance and decreased central adiposity, especially in the older adult population.[67]

**Improvements in Mental and Physical Health**

*Mental Health*

Caregivers consistently described harvesting as a positive experience which led to benefits beyond access to fresh vegetables. Caregivers associated harvesting with improvements in mental health including reprieve from stresses of caregiving, enhanced spirituality, connectedness with nature, and sense of community. Several caregivers connected the therapeutic aspect of harvesting and being in nature to their caregiving experience:

> P9: Just being able to get out, I mean from the caregiver side, is a little bit of a reprieve too. To go outside and get some fresh air and do something beyond just taking care of things at home and going to medical appointments and that type of thing. I guess, uplifting as a caregiver.

Some caregivers described harvesting as a distraction and reprieve from the stressors of caregiving, noting that their schedules are busy fulfilling their roles as a caregiver, but harvesting was still allowing them to care for their survivor by providing fresh vegetables, but in a much more positive and enjoyable environment:

> P9: I just feel with so many caregiving things, it feels like another chore, that you know crowding into my life and all. And this doesn't feel like that at all, it's a real positive experience.

These results align with several other garden studies demonstrating improved mental health with gardening.[21,24,25]

Harvesters also described the spiritual and mental benefit of being outside in nature. One caregiver said:

> P7: Here you are at the garden, and it's so serene and so beautiful. And it's pretty quiet. It's almost like a walk in the park… not only does it feed your mind, soul, your body. It does all of those things.

Research suggests that having a strong spiritual well-being can serve as protective factor against the psychological distresses of caregiving and create more meaning in the caregiving role.[70,71] Physically being at the garden had an impact on many caregivers as they mentioned the impact of using their hands in nature and being out in the sunshine and rain as improving their mental health. This benefit was described as being an unexpected outcome of harvesting but strongly impacted their mental health. The association of time spent outdoors with improved mental health is well documented.[72–74] Spending time in a garden has been described as creating a sense of calm and wellbeing in general populations.[74]

A sense of belonging and support was also associated with improvements in mental health. Harvesting provided a unique experience for caregivers to feel supported:

> P7: Sometimes you feel that you are in this maybe by yourself. And then you almost have a built-in support system when you go to the garden, you realize you are not the only person going through it. You don't even have to talk about it you just feel that support there.

Others described gratefulness for people providing a service for caregivers:

> P5: I just thought it encouraging … the sense that somebody cares enough to reach out change people's habits for healthy eating.

> P6: I thought of the dedication of all the people that were working at the garden.

Caregivers acknowledged the extensive labor required for the garden and expressed gratitude for the workers and volunteers who maintained the GOH. While caregivers were often taking care of someone else, they were especially aware and thankful for other people taking care of them.

*Physical Health*

Most caregivers indicated an improvement in their physical health. Overall, participating in harvesting and increasing vegetable intake resulted in caregivers feeling better physically:

> P2: You just don't feel as bogged down. I don't know how to describe that scientifically, I think it just does make you feel a little bit better. You feel better. You don't just feel sluggish.

While the caregivers were not initially asked about dietary changes, the theme of improved dietary patterns emerged overwhelmingly as caregivers described changes in their physical health. Most of the caregivers responded to “How has harvesting impacted your health?” with a response related to improvements in vegetable intake and dietary patterns. Secondarily, caregivers associated the activity of harvesting with improving their physical health. It was evident caregivers associated changes in dietary patterns with improved physical health as most caregivers connected eating more vegetables to physically feeling better.

Although most caregivers attributed perceptions of improved physical health to eating a healthier diet, some described increasing physical activity as a result of harvesting. One caregiver described their experience harvesting:

> P4: You are involved in physical activity, bending over, looking, walking down the aisles and things like that.

Other caregivers described that harvesting also led to an increase in physical activity outside of the garden. Caregivers described a momentum effect of healthy behaviors:

> P7: You just feel better. Because you feel better you just say “let’s go out for a walk” or just continue exercise because you know you are putting good things in your body.

Harvesting at the GOH and eating a healthy diet provided motivation for other healthy behaviors and physical activity beyond harvesting. Because caregivers felt the positive physical effects of harvesting and improving their diet, they wanted to continue with further healthy behaviors. Harvesting started a “snowball effect” with caregivers, healthy behavior changes encouraged further healthy behavior changes. One caregiver even

described how engaging in physical activity at the GOH gave them more confidence to be more active at home.

With evidence suggesting caregiving responsibilities interfere with a caregivers' ability to engage in physical activity, harvesting at the GOH provides an opportunity for caregivers to engage in physical activity while simultaneously assisting and spending time with their survivor.[37] Furthermore, physical activity interventions among cancer caregivers have shown to improve mental health, aerobic fitness, physical functioning and energy levels.[45,46,48] The Physical Activity Guidelines for Americans classify gardening as a multi-component physical activity program, combining muscle strengthening, balance, and aerobic activity.[75] The physical activity guidelines for older adults emphasize the importance of multi-component activities given older adults are at increased risks for falls, warranting exercises which focus on strength and balance as a preventive mechanism.[75] The physical outcomes of gardening in the older adult population have been studied; after a 10 week horticultural therapy program, older adults participating in gardening activities improved strength, balance, flexibility, and agility.[76] With 65 being the average age of caregivers in this study, harvesting at the garden can provide an opportunity to meet physical activity recommendations specific to this population.

**Improvements in Social Support**

Caregivers enjoyed the community aspect of the GOH and specifically benefitted from the opportunity of spending quality time with their survivor, meeting new people, and interacting with students and volunteers the GOH. The GOH was frequently described as a social activity, where caregivers were not only looking forward to

harvesting, but spending time with their survivor and seeing familiar faces. Many caregivers valued the opportunity to engage in an activity with their survivor outside of the regular caregiving duties,

> P9: It seemed like every conversation we had the last two years has been, not every conversation but we have a lot of conversations about (their) health. I think it weighs on (them) that we are always talking about (them) and going places we are always taking (their) medical care so it was a nice break from things we could talk about.

Similarly, one caregiver described the multiple surgeries their survivor went through and the countless hours they spent at the hospital and how the GOH improved their cancer experience:

> P8: It's just something that we can do that is very positive as far as the cancer experience, it's just different. We like being outdoors, we love being in the garden. We used to live out in the country and have a big garden but we don't anymore so, it's just fun!

The GOH did not only facilitate quality time harvesting, but also at home. Caregivers spoke about spending more time planning for meals, shopping and preparing meals together with their survivor:

> P1: We are spending more time together, quality time just cooking together. We're doing meal preparation together, shopping together.

The GOH provided them with a positive experience to look forward to and incorporate into their routine throughout the week.

Caregivers appreciated the interactions with other harvesters, students and volunteers. Although caregivers did not always know who was a caregiver and who was a survivor, they expressed the sense of community from seeing familiar faces and meeting new people. Caregivers consistently expressed appreciation for the students and volunteers for their energy and knowledge at the GOH:

> P8: all of [the students] are just so positive and friendly, it just made it a really nice experience.

Caregivers associated the positive energy and excitement of the students to the overall positive experience harvesting. Several caregivers expressed how the GOH had such an impact on them that they wanted to share their positive experience with others:

> P7: I just tell everybody. What a wonderful, wonderful opportunity it is. It's not just for getting good, healthy, organic food but it's just… it's food for the soul.

Caregivers told their neighbors, supports groups and friends about the GOH to encourage them to participate in upcoming years.

Caregivers overwhelmingly described the quality time spent with their survivor. Harvesting at the garden provided an opportunity for caregivers to connect with their survivors outside of their daily medical-related routines. The quality time surpassed the time harvesting as the caregiver/survivor dyads made changes to their routines by creating more time for meal preparation and planning together. Trudeau et al. found that cancer caregivers desire connection, especially with the spouse for whom they provide care.[17] Research is mixed on the impact a cancer diagnosis has on a survivor and caregiver. The caregiving role can strain the relationship between the caregiver and survivor as roles are changing and time together is mostly spent around cancer related

tasks.[17] However, especially in spousal dyads, caregiving can improve the relationship between the caregiver and survivor.[33] Mutuality, the positive quality of the relationship between the caregiver and care-receiver influences outcomes in caregivers and survivors.[77] Indeed, evidence suggests that better relationship quality is associated with less caregiver burden, strain, and resentment.[18,78] Harvesting at the GOH provided an opportunity for a fun and enjoyable activity for the caregivers and survivors to engage in together throughout the week, creating a stronger relationship and reducing the feelings of caregiver burden.

Caregivers also described the perceived community of support created by seeing and meeting other caregivers and survivors. In the same work by Trudeau et al., caregivers described the need to connect with people who "get" it. The caregiving experience has unique challenges that caregivers need to share with people who have the ability to emphathize.[17] The GOH provided a physical space for caregivers to interact with one another and feel like they were not alone in their caregiving experience. This sense of connection among caregivers was also described by Anton et al., where caregivers described the shared experience of caregiving as being especially beneficial to participating in an exercise program.[45]

**Maintenance of Positive Behaviors**

Even though the harvest season had concluded, the vast majority of caregivers indicated they are still keeping up with the improved dietary patterns and behaviors they experienced from harvesting at the GOH. Caregivers reported making conscious efforts to maintain their increased vegetable intake after the harvest season:

P1…we have a salad every day and less of the fatty foods, restaurants, you know or fast food. We're doing a lot more cooking at home.

Many caregivers reported still using the recipes they first tried during the harvest season, while other reported preserving their harvest by freezing surplus to use throughout the winter:

P9: I have a mess of freezer pesto this year, so just two weeks ago I pulled out a jar of pesto.

Others mentioned they are continuing to buy produce from the grocery store that they enjoyed harvesting from the GOH:

P8: We pretty much buy all of our fruits and vegetables from Whole Foods and you can get the stuff that was in the garden there, so we do.

Some caregivers valued the perceived freshness and sustainability of harvesting local produce and reported being more mindful to buy local, seasonal produce when available as a result:

P9: I go to farmers markets and local farms more often to buy things.

Overall, these results demonstrate an improvement of HRQOL in caregivers who harvested at the GOH. The Center for Disease Control (CDC) includes the following aspects in HRQOL, "physical and mental health perceptions (e.g., energy level, mood) and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status."[79] The four overarching themes align with this definition as improving multiple facets of HRQOL. Quality of life has been measured in several caregiver studies and is associated with caregiver burden and years spent caregiving. Caregivers who report a high burden of care or who have been caregiving

multiple years indicated lower quality of life.[80] Quality of life has also been shown to be interdependent among caregivers and survivors, further providing support for dyadic quality of life interventions.[80,81]

The final question in the questioning route asked participants to identify the "most beneficial piece of the GOH program." The results were highly variable, however, over half of the participants identified the access to and increased intake of vegetables as the most beneficial piece of the GOH program. Other answers included improved mental health, improved relationship with survivor, and feeling encouraged as a caregiver. Although the responses were varied, they encompass the overarching themes identified in all interviews. Harvesting at the GOH included many benefits, and each caregiver has unique perceptions of these benefits.

**Limitations**

Although this study provides evidence for the positive health benefits caregivers experienced from harvesting, there are limitations to consider. This study had a small sample size, N=9. Only 32 GOH participants met the inclusion criteria and were sent a recruitment email. Of these, 28% responded and participated in an interview. Some of the participants recognized the primary author who facilitated the interviews as this researcher also worked at the GOH and interacted with participants. The familiarity of the interviewer may have led to bias as participants may have given reserved responses. This study focused on the effect harvesting had on caregivers health, however, some caregivers may have attributed their benefits to other programs offered throughout the garden season including gardening and cooking classes, though during interviews the primary author kindly directed participants to focus on the GOH alone.

## Implications for Research and Practice

The results of this study will be used to inform future interventions to support cancer caregivers. This study provides preliminary support for the use of harvesting at an urban garden to improve the health of cancer caregivers. Research among cancer caregivers is conflicting and difficult to compare based on the wide variety of cancer caregiving experiences because of types of cancer and length of caregiving. To better understand the overall cancer caregiving experience and health behaviors of caregivers, further research is needed to identify key needs of cancer caregivers to better inform interventions. Qualitative studies investigating the health impacts of cancer caregiving can provide further insight into this unique population. Suggestions for future research include conducting an additional urban harvesting study but taking measures of physical health, mental health, and quality of life pre and post-harvest season. This will provide more evidence of measurable changes in health rather than perceptions of change alone.

Additionally, this study provides evidence for the inclusion of caregivers in lifestyle recommendations and interventions for cancer survivors. This study demonstrated caregivers and survivors made many positive health behavior changes together and can benefit from dyadic interventions. Both survivors and caregivers are at risk for negative health impacts, and allowing them to support and encourage each other through health interventions may improve outcomes.

# Chapter 5: Health Perceptions of Cancer Caregivers Harvesting at an Urban Garden

**Objective:** To identify perceived outcomes and changes in quality of life among cancer caregivers harvesting at an urban garden.

**Design:** Mixed methods research design utilizing a self-administered online questionnaire and telephonic semi-structured interviews.

**Setting:** Urban Garden in Columbus, Ohio.

**Participants:** Nine cancer caregivers who harvested at an urban garden were recruited via email.

**Phenomenon of Interest:** The health perceptions of cancer caregivers who harvested at an urban garden.

**Analysis:** Interview transcripts were analyzed using conventional content analysis (NVivo qualitative analysis software) to identify overarching themes and subthemes.

**Results:** Caregiver responses resulted in identification of four overarching themes: (1) improved physical and mental health, (2) improved dietary patterns, (3) improved social support, and (4) maintenance of healthy behaviors.

**Conclusions and Implications:** Harvesting at an urban community garden improved physical and mental health, dietary patterns, and social support for cancer caregivers. These results will be used to inform and test future interventions designed to support caregivers of cancer survivors.

## Introduction

Because of the acute and long-term effects of cancer, the burden of cancer is often shared with unpaid, informal caregivers.[4] As cancer treatments are becoming commonly delivered in the outpatient setting, informal caregivers are needed to pick up where the health care team leaves off between and after treatments.[1] Caregivers perform various roles including accompanying cancer survivors to appointments, communicating with providers, assisting in decision making, providing medical care at home, providing emotional support, and assisting with activities of daily living.[4,5]

The experience of cancer caregiving is demanding and caregivers often experience negative psychosocial, behavioral, and physiological effects on their daily lives and health.[6] Research suggests interventions targeting cancer caregivers can improve caregiver health and the overall caregiving experience.[10] Moreover, targeted caregiver interventions may also contribute to improved lifestyle behaviors and mental health in the cancer survivor, via what is known as a spillover effect.[12] Such interventions hold the potential for sweeping improvements in health outcomes in these high-risk populations. Urban community gardening and harvesting is one approach to encouraging healthy lifestyle behaviors in cancer caregivers. Harvesting at community gardens has been shown to improve fruit and vegetable intake, physical activity levels, and mental health.[20–23] Community gardens also foster a sense of community and increase social interactions.[20,23–25] Given the range of health benefits and increased social connectedness resulting from participation in community gardens, gardening may be a novel intervention to improve the health and quality of life of cancer caregivers.

James*Care* for *Life* (JCFL) is an extension of Ohio State University's Comprehensive Cancer Center (OSU-CCC). This department provides a variety of programs and resources for cancer survivors and caregivers through their cancer journey. The largest nutrition program is the Garden of Hope (GOH), a community garden located on The Ohio State University's Waterman Farm. This two-acre garden features a variety of vegetables, fruits, and herbs for cancer survivors and their caregivers. There are currently no studies that examine the impact of urban harvesting on cancer caregivers' physical and mental health perceptions and overall quality of life. The GOH is one of few cancer caregiver gardens linked directly to a Comprehensive Cancer Center. This setting is an ideal and unique environment to examine the relationship between urban harvesting and health of cancer caregivers. Thus, a better understanding of the impact of the GOH on cancer caregivers will provide data which can lead to improved interventions for this understudied and vulnerable population. The purpose of this study was to identify perceived outcomes and changes in quality of life among cancer caregivers harvesting at an urban community garden.

**Methods**

In order to meet the predetermined objectives, the study employed a mixed methods design to provide a rich description of the unique perceptions and experiences of cancer caregivers harvesting at the GOH. A semi-structured interview format was utilized to elicit the perceptions of caregivers using a predetermined questioning route. In addition, a self-administered supplemental questionnaire was provided to collect basic demographic data and caregiver specific history. Qualitative research methods were appropriate to use to understand the unique perceptions and experiences of

cancer caregivers harvesting at the GOH. Utilizing a questioning route of open ended questions and follow-up questions in individual interviews, the benefits of caregivers participating in a four month harvest season were determined. This project was reviewed and approved by the Ohio State University Institutional Review Board.

JCFL staff sent secure recruitment emails to every caregiver who harvested at the GOH three or more times during the 2018 harvest season. These individuals were identified using harvest attendance records maintained by JCFL staff over the course of the harvesting season, and this selection method served to ensure recruitment of individuals who had adequate exposure to the GOH for reflection of their experiences. Recruitment emails were sent one month after the conclusion of the harvest season to allow time for reflection on the harvest season and identification of maintenance of behaviors. All individuals contacted were provided a description of the study, the risks and benefits of participating, assurance that all information would be kept confidential, and confirmed there was no penalty for choosing not to participate. Caregivers who expressed interest in participation were provided a secure link to complete a quantitative self-administered questionnaire to collect basic demographic and caregiver specific history.

Once participants completed the survey, they scheduled a phone interview. The primary author facilitated all interviews. This researcher was trained by qualitative research expert and was mentored throughout the interviews to improve interview skills. The primary author called each caregiver at the scheduled interview time. First, participants were reminded of the purpose of the study and were explained the structure of the interview. Next, the participants were asked if they agreed to have their interview recorded. The

researcher followed the semi-structured interview questioning route and used reflective listening and probing to elicit depth in participant responses. All interviews were audio recorded using a digital recording device and the recordings were uploaded to a secure database and then transcribed verbatim by the primary author. All identifying information was removed. At the completion of the interview, the researcher thanked the participant for their time and asked for an address for delivery of a $10 gift card. The gift card was mailed to participants homes and the research team required a confirmation email when the caregivers received their gift card.

**Analysis**

Data from self-administered quantitative questionnaires were analyzed for descriptive statistics, including calculations of means and standard deviations. The audio transcripts were analyzed to identify themes and patterns through inductive processes of conventional content analysis and the constant comparison method.[58,64] In addition to the primary author who conducted the interviews, one additional researcher reviewed the transcripts to evaluate themes and establish codes. The transcripts were first reviewed individually to identify overarching themes, after which the researchers came together to compare themes and discuss initial codes for the codebook. Accordingly, the primary author created an initial codebook consisting of codes, definitions of codes, and examples. The researchers met again to review the codebook and discuss any changes before finalizing the codebook. The final codebook consisted of six individual codes that were agreed upon by both researchers. As a calibration test, the researchers individually coded four interview transcripts and met to compare codes. The researchers discussed every code and compared and calculated agreements and disagreements. Any coding

discrepancies were discussed and the research team came to a consensus. After reviewing several transcripts, the researchers determined saturation was achieved after nine interviews. Thematic saturation was achieved when no new themes were emerging from the interview transcripts, and no further interviews were conducted.[63]

To calculate interrater reliability, the two researchers individually coded the fifth transcript in Nvivo. The transcripts were compared through the Nvivo comparison query to calculate the kappa statistic. The results showed that the coders had a 0.81 kappa statistic, exhibiting almost perfect agreement.[63] Additionally, the percent agreement was calculated by dividing the total number of agreements by the total number of codes. The result was an 89% agreement. Once this strong interrater reliability was established, the primary author independently coded the remaining four transcripts. Once all transcripts had been coded by hand, they were coded using the Nvivo software to evaluate overarching themes and identify subthemes. Subthemes were determined by identifying common ideas within each theme. Subthemes that were present in over half of the transcripts were given a subcode to track the subthemes throughout the transcripts.

## Results

Nine caregivers participated in semi-structured interviews. Table 5.1 details the characteristics and caregiving history of the participants. All of the participants were Caucasian and five were female and four were male. The majority of participants were spouses of the cancer. Over half of the survivors were still in active treatment. The average age of the participants was 65.4 ± 7.1, while the ages ranged from 54-75 years of age. Over half of the participants had harvested at the GOH for the first time this year, the rest had completed two seasons of harvest. The average years of caregiving was 4.3 ± 3.6 years, and the range included 1-12 years caregiving. The majority of participants also participated in a gardening or nutrition class through JCFL during the harvest season.

Four overarching themes emerged from the interviews (1) Improved dietary patterns, (2) improved perceptions of mental and physical health, (3) enhanced social support, and (4) maintenance of positive behaviors. Summary data of themes and subthemes along with illustrative quotes are provided in table 5.3.

*Improved Dietary Patterns*

Caregivers described the development of various new behaviors which served to positively shift their dietary patterns to align with the evidence-based guidelines promoting a primarily plant-based diet. The United States Department of Agriculture (USDA) defines dietary patterns as “the quantities, proportions, variety, or combination of different foods, drinks, and nutrients (when available) in diets, and the frequency with which they are habitually consumed.” While every caregiver reported increasing the overall amount vegetables they consume, most (i.e., ≥50%) discussed increasing the

variety of vegetables they consumed as a result of harvesting at the GOH. Others described shifting the proportions of the food groups in their dietary patterns by focusing on the plate method, filling half of the plate with vegetables, as an approach to consistently increase the amount of vegetables consumed. Many caregivers described adopting a plant-based diet in support of their survivors health, and harvesting at the GOH not only improved the dietary patterns of the caregivers, but enabled the caregivers to better provide a plant-based diet for the survivor they provide care for.

Caregivers described several behaviors including trying new foods, spending more time planning and preparing meals, and continuing to buy more vegetables and local produce even after the harvest season ended. Caregivers appreciated the recipes and preparation resources provided by JCFL and dietetics students as these resources encouraged caregivers to try new and unfamiliar foods.

*Mental Health*

Caregivers consistently described harvesting as a positive experience which led to benefits beyond access to fresh vegetables. Caregivers associated harvesting with improvements in mental health including reprieve from stresses of caregiving, enhanced spirituality, connectedness with nature, and sense of community. Several caregivers connected the therapeutic aspect of harvesting and being in nature to their caregiving experience. Some caregivers described harvesting as a distraction and reprieve from the stressors of caregiving, noting that their schedules are busy fulfilling their roles as a caregiver, but harvesting was still allowing them to care for their survivor by providing fresh vegetables, but in a much more positive and enjoyable environment. Physically being at the garden had an impact on many caregivers as they mentioned the impact of

using their hands in nature and being out in the sunshine and rain as improving their mental health. A sense of belonging and support was also associated with improvements in mental health. Harvesting provided a unique experience for caregivers to feel supported and understood by being surrounded with other caregivers.

*Physical Health*

Most caregivers indicated an improvement in their physical health. Overall, participating in harvesting and increasing vegetable intake resulted in caregivers feeling better physically. While the caregivers were not initially asked about dietary changes, the theme of improved dietary patterns emerged overwhelmingly as caregivers described changes in their physical health. Most of the caregivers responded to “How has harvesting impacted your health?” with a response related to improvements in vegetable intake and dietary patterns. Secondarily, caregivers associated the activity of harvesting with improving their physical health. It was evident caregivers associated changes in dietary patterns with improved physical health as most caregivers connected eating more vegetables to physically feeling better. Caregivers also reported increasing physical activity through gardening and also increasing overall physical activity at home as a result of harvesting. Because caregivers felt the positive physical effects of harvesting and improving their diet, they wanted to continue with further healthy behaviors. Harvesting created momentum within caregivers, healthy behavior changes encouraged further healthy behavior changes.

*Social Support*

Caregivers enjoyed the community aspect of the GOH and specifically benefitted from the opportunity of spending quality time with their survivor, meeting new people,

and interacting with students and volunteers the GOH. The GOH was frequently described as a social activity, where caregivers were not only looking forward to harvesting, but spending time with their survivor and seeing familiar faces. Many caregivers valued the opportunity to engage in an activity with their survivor outside of the regular caregiving duties. Caregivers spoke about spending more time planning for meals, shopping and preparing meals together with their survivor. The GOH provided them with a positive experience to look forward to and incorporate into their routine throughout the week.

Caregivers appreciated the interactions with other harvesters, students and volunteers. Although caregivers did not always know who was a caregiver and who was a survivor, they expressed the sense of community from seeing familiar faces and meeting new people. Caregivers consistently expressed appreciation for the students and volunteers for their energy and knowledge at the GOH. Caregivers associated the positive energy and excitement of the students to the overall positive experience harvesting. Several caregivers expressed how the GOH had such an impact on them that they wanted to share their positive experience with others, and discussed telling friends, neighbors, and support groups about the GOH.

*Maintenance of Positive Behaviors*

Even though the harvest season had concluded, the vast majority of caregivers indicated they are still keeping up with the improved dietary patterns and behaviors they experienced from harvesting at the GOH. Caregivers reported making conscious efforts to maintain their increased vegetable intake after the harvest season. Many caregivers reported still using the recipes they first tried during the harvest season, while other

reported preserving their harvest by freezing surplus to use throughout the winter. Others mentioned they are continuing to buy produce from the grocery store that they enjoyed harvesting from the GOH. Some caregivers valued the perceived freshness and sustainability of harvesting local produce and reported being more mindful to buy local, seasonal produce when available as a result.

**Discussion**

Consistent with several other garden studies, these results suggest that harvesting at an urban, community garden improves dietary patterns, physical and mental health, and social support. Increases in vegetable intake while participating in a hands-on garden experience is well documented.[23,24,50,69] Specifically, the access to fresh produce at a garden combined with nutrition education has shown to improve adherence to a plant based diet in children and adult populations.[20,24,53] The GOH provided access to produce and education for caregivers to more easily align their dietary patterns with a plant-based diet. Although this study did not measure physiological changes, some garden studies demonstrate that harvesting improved fasting blood glucose, HDL cholesterol and skin carotenoid levels.[22] Other studies show that participating in gardening increased physical performance and decreased central adiposity, especially in the older adult population.[67]

Harvesters frequently described the spiritual and mental benefit of being outside in nature. Harvesters described the garden as a positive experience that provided food for the body, soul and mind. Research suggests that having a strong spiritual well-being can serve as protective factor against the psychological distresses of caregiving and create more meaning in the caregiving role.[70,71] Physically being at the garden had an

impact on many caregivers as they mentioned the impact of using their hands in nature and being out in the sunshine and rain as improving their mental health. This benefit was described as being an unexpected outcome of harvesting but strongly impacted their mental health. The association of time spent outdoors with improved mental health is well documented.[72–74] Spending time in a garden has been described as creating a sense of calm and wellbeing in general populations.[74]

With evidence suggesting caregiving responsibilities interfering with a caregivers ability to engage in physical activity, harvesting at the GOH provides an opportunity for caregivers to engage in physical activity while simultaneously assisting and spending time with their survivor.[37] Furthermore, physical activity interventions among cancer caregivers have shown to improve mental health, aerobic fitness, physical functioning and energy levels.[45,46,48] The Physical Activity Guidelines for Americans classify gardening as a multi-component physical activity program. These activities combine muscle strengthening, balance, and aerobic activity.[75] The physical activity guidelines for older adults emphasize the importance of multi-component activities because older adults are at increased risks for falls and strength and balance are needed to prevent falls.[75] The physical outcomes of gardening in the older adult population have been studies. After a 10 week horticultural therapy program, older adults participating in gardening activities improved strength, balance, flexibility and agility.[76] With 65 being the average age of caregivers in this study, harvesting at the garden can provide an opportunity to meet physical activity recommendations.

Caregivers overwhelmingly described the quality time spent with their survivor. Harvesting at the garden provided an opportunity for caregivers to connect with their

survivors outside of the daily medical world. The quality time surpassed the time harvesting as the caregiver/survivor dyads made changes to their routines by creating more time for meal preparation and planning together. Trudeau et al. found that cancer caregivers desire connection, especially with the spouse for whom they provide care.[17] Research is mixed on the impact a cancer diagnosis has on a survivor and caregiver. The caregiving role can strain the relationship between the caregiver and survivor as roles are changing and time together is mostly spent around cancer related tasks.[17] However, especially in spousal dyads, caregiving can improve the relationship between the caregiver and survivor.[33] Mutuality, the positive quality of the relationship between the caregiver and care- receiver, influences outcomes in caregivers and survivors.[77] Evidence suggests that better relationship quality is associated with less caregiver burden, strain and resentment.[18,78] Harvesting at the GOH provided an opportunity for something fun and enjoyable for the caregivers and survivors to engage in together throughout the week, creating a stronger relationship and reducing the feelings of caregiver burden.

Caregivers also described the perceived community of support created by seeing and meeting other caregivers and survivors. Also in the Trudeau study, caregivers described the need to connect with people who “get” it. The caregiving experience has unique challenges that caregivers need to share with people who have gone through similar experiences.[17] The GOH provided a physical space for caregivers to interact with one another and feel like they were not alone in their caregiving experience. This sense of connection among caregivers was also described in the Anton et al. study where

caregivers described the shared experience of caregiving especially beneficial to participating in an exercise program.[45]

Overall, these results demonstrate an improvement of HRQOL in caregivers who harvested at the GOH. The Center for Disease Control (CDC) includes the following aspects in HRQOL, "physical and mental health perceptions (e.g., energy level, mood) and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status."[79] The four overarching themes align with this definition as improving multiple facets of HRQOL. Quality of life has been measured in several caregiver studies and is associated with caregiver burden and years spent caregiving. Caregivers who report a high burden of care or who have been caregiving multiple years indicated lower quality of life.[80] Quality of life has also been shown to be interdependent among caregivers and survivors, further providing support for dyadic quality of life interventions.[80,81]

**Limitations**

Although this study provides evidence for the positive health benefits caregivers experienced from harvesting, there are limitations to consider. This study had a small sample size, N=9. Only 32 GOH participants met the inclusion criteria and were sent a recruitment email. Of these, 28% responded and participated in an interview. Also of note, some of the participants recognized the primary author as this researcher also worked at the GOH and interacted with some participants. The familiarity of the interviewer may have led to bias as participants may have given reserved responses. This study focused on the effect harvesting had on caregivers health, however, some caregivers may have attributed their benefits to other programs offered throughout the

garden season including gardening and cooking classes, though during interviews the primary author kindly directed participants to focus on the GOH alone.

**Implications for Research and Practice**

The results of this study will be used to inform future interventions to support cancer caregivers. This study provides preliminary support for the use harvesting at an urban garden to improve the health of cancer caregivers. Research among cancer caregivers is conflicting and difficult to compare based on the wide variety of cancer caregiving experiences because of types of cancer and length of caregiving. To better understand the overall cancer caregiving experience and health behaviors of caregivers, further research is needed to identify key needs of cancer caregivers to better inform interventions. Qualitative studies investigating the health impacts of cancer caregiving can provide further insight into this unique population. Suggestions for future research include conducting an additional urban harvesting study but taking measures of physical health, mental health, and quality of life pre and post-harvest season. This will provide more evidence of measurable changes in health rather than perceptions of change alone.

Additionally, this study provides evidence for the inclusion of caregivers in lifestyle recommendations and interventions for cancer survivors. This study demonstrated caregivers and survivors made many positive health behavior changes together and can benefit from dyadic interventions. Both survivors and caregivers are at risk for negative health impacts, and allowing them to support and encourage each other through health interventions may improve outcomes.

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Appendix A: Participant Demographics

| Participant Characteristics (N=9) | | % (n) |
|---|---|---|
| **Age (average years ± SD)** | | 65.4 ± 7.1 |
| **Sex** | Male | 44% (n=4) |
| | Female | 56% (n=5) |
| **Race / Ethnicity** | White / Caucasian | 100% (n=9) |
| | Black / African American | 0% (n=0) |
| | Asian | 0% (n=0) |
| | Hispanic/Latino | 0% (n=0) |
| **Relation to Cancer Survivor** | Spouse | 78% (n=7) |
| | Friend | 11% (n=1) |
| | Sibling | 0% (n=0) |
| | Neighbor | 0% (n=0) |
| | Other Family | 11% (n=1) |
| **Survivor Caregiving for in active treatment?** | Yes | 56% (n=5) |
| | No | 44% (n=4) |
| **First or second year at the GOH?** | First | 56% (n=5) |
| | Second | 44% (n=4) |
| **Years providing care for cancer survivor (average ± SD)** | | 4.3 ± 3.6 |
| **Years providing care for cancer survivor** | 1-3 years | 56% (n=5) |
| | 4-6 years | 22% (n=2) |
| | 7-10 years | 11% (n=1) |
| | 11+ years | 11% (n=1) |
| **Participation in other gardening or nutrition programs** | Yes | 67% (n=6) |
| | No | 33% (n=3) |
| **Specific programs** | Container Gardening | 11% (n=1) |
| | How to Start a Home Vegetable Garden | 22% (n=2) |
| | Maintaining Your Home Vegetable Garden | 22% (n=2) |
| | Make the Most Out of Your Vegetables | 0% (n=0) |
| | Hand-On Cooking | 0% (n=0) |
| | Healthy Eating for the Cancer Survivor | 22% (n=2) |
| | Living a Plant Based Lifestyle | 22% (n=2) |
| | Shopping with the Expert | 0% (n=0) |
| | Other | 0% (n=0) |

Table A.1 Participant Demographics

Appendix B: Recruitment Letter to Participants

Dear Caregiver,

Hello, my name is Kaleigh Carpenter. I am a graduate student at The Ohio State University in the Medical Dietetics Division of The College of Medicine, and I am conducting research for my masters thesis.

I am studying the health perceptions of cancer caregivers harvesting at the Garden of Hope. The information you share with me will be of great value in helping me to complete this research project and will remain confidential.

If you agree to participate, you will be directed to a short survey by clicking the link below and will participate in a brief phone interview which will take 20- 30 minutes of your time. Again, this data will be kept confidential, and your name will not be linked to any data collected. This study has been approved by the OSU Institutional Review Board, and there are no other expected risks of participation.

Participation is completely voluntary. If you decide not to participate, there will be no penalty or loss of benefits to which you are otherwise entitled. You can decline to answer any question, or stop participating at any time, without any penalty or loss of benefits to which you are otherwise entitled. If you have any additional questions concerning this research, please feel free to contact me, my thesis advisor, Colleen Spees (spees.11@osu.edu), or our university research office at any time (800-678-6251).

If you choose to participate, you may click on the link below to access a short survey. Please email me at garden@osumc.edu to schedule your short interview. Thank you for your consideration!

Sincerely,

Kaleigh Carpenter
SURVEY LINK HERE

Appendix C: Participant Questionnaire

Health Perceptions of Cancer Caregivers Harvesting at the Garden of Hope

**Demographic Information:**

1. What is your age: _____

2. What is your race/ethnicity?

   _____ Latino or Hispanic _____ White or Caucasian
   _____ Black or African American _____ Native American or American Indian
   _____ Asian or Pacific Islander _____ Other: Please list:
   _____
   _____ I do not know. _____ I prefer not to answer.

3. What is your gender?

   _____ Female _____ Male _____ Transgender or Other
   _____ I do not want to answer.

4. What is your relationship with the cancer survivor you provide care for?

   _____ Spouse _____ Sibling _____ Neighbor
   _____ Friend _____ Other family _____ Other:_____

5. Is the survivor you care for currently in active treatment (chemo, radiation, etc)?
   _____ Yes _____ No

6. How many years have you been providing care for a cancer survivor?

**OVER**

7. Other than harvesting, did you attend any nutrition or gardening programs during this year's harvest season? Please check which programs.

□ Container Gardening
□ How to Start a Home Vegetable Garden
□ Maintaining your Home Vegetable Garden
□ Make the Most Out of Your Vegetables
□ Hands-On Cooking
□ Healthy Eating for the Cancer Survivor
□ Living a Plant Based Lifestyle
□ Shopping with the Expert
□ Other: _____

8. Is this your first or second season harvesting at the Garden of Hope?

**Thank you so much for your time and participation in the survey and the interviews!**

# Appendix D: Semi-Structured Interview Guide

1. Describe your overall experience at the Garden of Hope this past summer.

    a. Probe: How was the Garden of Hope was a positive experience?

2. How has harvesting at the Garden of Hope impacted your overall health?

    b. Probe: How has harvesting impacted your physical health?

    c. Probe: How has harvesting impacted your mental health?

3. What types of changes, if any, did you make to your diet or lifestyle as a result of participating in the Garden of Hope program?

    - Probe: Is there anything you still do now?

4. How has harvesting at the Garden of Hope impacted your relationships?

    - Probe: How has harvesting at the Garden of Hope impacted your relationships with your cancer survivor you care for?
    - Probe: Did harvesting at the garden impact your routine together?
    - Probe: Did you create any new relationships at the Garden of Hope?

5. Overall, what did you feel was the most beneficial piece of the Garden of Hope program?

Appendix E: Interview Data- Illustrative Quotes

| Themes | Participant Quotes Supporting Themes |
|---|---|
| *Improved Mental Health* | |
| Spiritual | P7: Whoever thought you could get away from, here you are in the middle of the city. Here you are at the garden, and it's so serene and so beautiful. And it's pretty quiet. It's almost like a walk in the park, just to get away from the news, the bombardment of traffic and horns and it's not only does it feed your mind, soul, your body. It does all of those things. |
| Reprieve from Caregiving | P9: Just being able to get out, I mean from the caregiver side, is a little bit of a reprieve too. To go outside and get some fresh air and do something beyond just taking care of things at home and going to medical appointments and that type of thing. I guess, uplifting as a caregiver |
| Positive Experience | P8: When [my spouse] is in the hospital I'm there with her all the time. And this was a different kind of experience which was very positive. The other one is a positive experience because everyone is wonderful but it's different situation. It's painful.<br><br>P2: Obviously the food part was very great in coming to get free food and new things, getting to try that out. But it was more than that I think. I liked I feel like the mental health part was probably the biggest benefit. |
| Nature | P5: You know, you get something out of putting your hands in the dirt, helping other people and you're helping yourself as well.<br><br>P6: Just being out there, meeting the people, getting out in the sunshine, or the rain. Yea, I'm sure it was good being outside it helps for the mental health. |

Continued

Table E.1 Interview Data- Illustrative Quotes

Table E.1 continued

| | |
|---|---|
| *Improved Physical Health* | |
| Physical Activity | P9: I think it was good for me to get out and move around. You know it just, building my confidence that I can do that and do more of that at home and be outside more at home.<br><br>P4: It's just different than, say, being in a classroom seated. You are involved in physical activity, bending over, looking, walking down the aisles and things like that. |
| Motivation for Healthy Behaviors | P7: You just feel better. Because you feel better you just say "let's go out for a walk" or just continue exercise because you know you are putting good things in your body. We can say "let's go do this bike ride" |
| Increased Energy | P2: You just don't feel as bogged down. I don't know how to describe that scientifically, I think it just does make you feel a little bit better.<br><br>P7: You feel better. You don't just feel sluggish. |
| *Improved Dietary Patterns* | |
| Eating Behaviors | P1: It's more of a variety of salads that we enjoyed. Instead of just lettuce and carrots you know that kind.<br><br>P6: Eating the fresh picked stuff was certainly healthy and made us look for recipes that we might not have otherwise tried.<br><br>P9: Wherever I can I use fresh vegetables.<br>especially this summer, 2 veggies rather than meat and potatoes. Even to the point where I'd say at least 2<br>days a week we have meatless dinners. A lot more fish and veggies so that was a big shift cause (survivor) always had to have potatoes or noodles or something. |

Continued

Table E.1 continued

| | |
|---|---|
| Access | P2: It certainly helps to go to the garden and get those green things.<br><br>P8: We got a lot of free vegetables |
| Diet Quality | P7: We are eating a lot more kale!<br><br>P1: Well we eat a lot better. You know vegetables and stuff, we have a salad every day |
| Knowledge | P4: It's learning about the produce and also the courage to try something that you haven't tried before. |
| Conscious Food Choices | P2: I know particularly about trying to eat like half your plate should be vegetables are greenery or fresh greenery or that kind of thing so we're kind of thinking more along those lines of trying to balance things a little bit better that way. |
| Support for Eating Behaviors | P3: We were already pretty conscious of enjoying more vegetables, but this gave us an extra little push. So that was good.<br><br>P6: We had consulted nutritionists on a couple of occasions during the course of [their] diagnosis and treatment, so we had learned about the plant based diet. But this was a little extra push in a way that made it more fun, because we get help to plan our menus according to the harvest. |
| I*mproved Social Support* | |

Continued

Table E.1 continued

| | |
|---|---|
| Quality Time with Survivor | P1: We are spending more time together, quality time just cooking together. We're doing meal preparation together, shopping together.<br><br>P8: I thought that was a really neat experience going out there. It was fun and everyone was nice and it was just.. NAME and I would do it together and it was a great experience.<br><br>P8: It was a different kind of experience than going to the other part of the James and that was a very positive thing we could do together. And we both like it there. |
| Social Interaction | P7: I guess sometimes you feel that you are in this maybe by yourself. And then you almost have a built in support system when you go to the garden, you realize you are not the only person going through it. You don't even have to talk about it you just feel that support there.<br><br>P3: The students and the folks that helped out there were all very helpful and energetic and made it an enjoyable experience. |
| Sharing Experience with Others | P7: I just tell everybody what a wonderful, wonderful opportunity it is. It's not just for getting good, healthy, organic food but it's just, like I said before, it's food for the soul. I just think it's a wonderful, wonderful opportunity and experience for everybody. |
| *Maintenance of Positive Behaviors* | |
| Dietary Patterns | P9: We've done some where we've bought fresh vegetables and flash frozen them and kept them. We've got a big stash of green beans in my freezer for dinner. I think it's not just a summertime thing. It's knowing throughout the year we'll use and go to those sources.<br><br>P2: we are trying to make sure our meal is more balance on the plate kind of trying to do that vegetables. We are trying to work on that. Some meals are better than others. |

Continued

| | |
|---|---|
| Shopping | P8: We pretty much buy all of our fruits and vegetables from Whole Foods so you can get the stuff that was in the garden there, so we do.<br><br>P7: I continue to buy kale |
| Meal Preparation | P8: [my spouse] continues to look for new recipes and vegetables, we just eat a lot of that stuff. |

Table E.1 Interview Data- Illustrative Quotes

Presentation of themes identified from qualitative analysis, including illustrative quotes which were identified during the analysis process and serve as key examples of each theme.

Appendix F: Recruitment and Participant Flow Through Study


Figure F.1 Recruitment and Participant Flow Through Study