An Educational Intervention to Alleviate the Effects of Burden of Chronic Illness Care: Presentation of a Caregiver Toolkit to Increase Awareness Among Primary Care Providers and Family Caregivers

Ashley Fuller

Follow this and additional works at: https://scholarworks.umass.edu/nursing_dnp_capstone

Fuller, Ashley, "An Educational Intervention to Alleviate the Effects of Burden of Chronic Illness Care: Presentation of a Caregiver Toolkit to Increase Awareness Among Primary Care Providers and Family Caregivers" (2017). Doctor of Nursing Practice (DNP) Projects. 95.
Retrieved from https://scholarworks.umass.edu/nursing_dnp_capstone/95

This Campus Access is brought to you for free and open access by the College of Nursing at ScholarWorks@UMass Amherst. It has been accepted for inclusion in Doctor of Nursing Practice (DNP) Projects by an authorized administrator of ScholarWorks@UMass Amherst. For more information, please contact scholarworks@library.umass.edu.
An Educational Intervention to Alleviate the Effects of Burden of Chronic Illness Care:
Presentation of a Caregiver Toolkit to Increase Awareness Among Primary Care Providers
and Family Caregivers

Ashley E. Fuller
University of Massachusetts Amherst, College of Nursing

DNP Project Chair: Terrie Black, DNP, MBA, CRRN, FAHA, FAAN
DNP Project Committee Member: Gabrielle Abelard, DNP, MS, BS, RN
Capstone Mentor(s): Karen Kemp
Debrah Dowd-Foley
Date of Submission: March 25, 2017
# Table of Contents

Abstract ........................................................................................................... 3
Introduction and background ............................................................................. 4
Problem statement ............................................................................................ 6
Review of literature ......................................................................................... 7
Theoretical framework ...................................................................................... 15
Project Design and Methods ........................................................................... 16
  Population, setting, and resources, organizational analysis ......................... 16
Toolkit Implementation ................................................................................... 19
  Goals and Objectives .................................................................................... 19
  Pre-toolkit preparation, toolkit development, and toolkit presentation .......... 19
Ethics and Human Subjects Protection ............................................................ 21
Results and outcomes ..................................................................................... 22
Discussion, facilitators, barriers, and future recommendations ....................... 24
Conclusion ...................................................................................................... 27
References ...................................................................................................... 29
Lazarus and Folkman’s Transactional Theory of Stress and Coping (Appendix A) ........ 33
Elder Services of Worcester Area (ESWA) Stakeholder support (Appendix B) .......... 34
Reliant Medical Group Stakeholder support (Appendix C) ................................ 35
Survey for Caregivers Post-Powerful Tools for Caregivers (PTC) Intervention (Appendix D) ................................................................. 36
PowerPoint Presentation Overview (Appendix E) ............................................. 38
Survey for Primary Care Providers’ Post-Presentation of Caregiver Toolkit (Appendix F) ................................................................. 45
HIPPA Informed Consent for Caregivers (Appendix G) ...................................... 47
Abstract

Background: The risk for burden among caregivers who provide care to elders with chronic illnesses is significant due to the negative effects on a caregiver as evidenced by psychological distress, depression, anxiety, social isolation, poor quality of life, and ineffective coping. Identifying caregivers who experience this burden is crucial to be able provide them with the opportunity to participate in community programs that focus on caregiver health. Purpose: The purpose of the integrative review DNP project was to highlight the importance of a psychoeducational and psychosocial training program, Powerful Tools for Caregivers (PTC), to increase awareness among Primary Care providers and caregivers. The PTC program demonstrated a positive effect in physical, psychological, and social well-being and helped caregivers’ to cope and communicate more effectively in the caregiving role. Toolkit: Creating a Caregiver Toolkit that consisted of information pertaining to the PTC program and community resources educated Primary Care providers and can assist them in identifying burden and service referral. The toolkit can also help caregivers to create community ties with both professional and nonprofessional services and support. Clinical Implications: Use of a Caregiver Toolkit in Primary Care helped to increase the knowledge among providers and family caregivers and focused on the use of community resources, support over the caregiving trajectory, and effective communication between caregivers and providers. Awareness of the PTC program among providers and caregivers positively correlated with a decrease in this burden, improved health status, and functioning, which lead to enhanced coping, problem solving, and communication.

Key words: Caregiver burden, family caregiver, primary care, chronic illness, coping, psychoeducation intervention
Introduction and Background

It is estimated that an astounding 34.2 million caregivers in the United States (U.S.) alone have provided regular, unpaid care to individuals 50 years of age and older within the last year (American Association of Retired Persons [AARP], 2015). A family caregiver is defined as an individual who provides a wide variety of regular and consistent unpaid care to elders with chronic conditions in the home environment (American Psychological Association [APA], 2016; Family Caregiver Alliance [FCA], 2014; National Alliance of Caregiving [NAC], 2010). Today, caregivers are in a unique position to provide rewarding activities by caring for elders in the community, however, when the level of stress exceeds the ability to provide appropriate care, negative outcomes and stress can impact their health and ability to carry out tasks that are required by caregiving (APA, 2016). This cycle of psychological distress results from the caregivers’ negative appraisal associated with their situations of ineffective coping, which ultimately leads to anxiety, depression, social isolation, and a suboptimal support system (APA, 2016; Kim, Chang, Rose, & Kim, 2011).

In a recent study that evaluated the core aspects of caregivers and the shift of caregiving in the future, the American Association of Retired Persons (AARP) (2015) report that the majority of caregivers are female (60%), family members (85%), and are on average 46 years old. Caregivers who provide regular caregiving hours, characterized by greater than 21 hours a week, are four times more likely to be a spouse; it is also reported that one in ten caregivers are older than 75 years of age (AARP, 2015). On average, caregivers provide approximately 24.4 to 41 hours each week, which can add additional stress, as they may lack financial assistance and emotional and physical support in the community leading to psychological distress and burden (AARP, 2015). Caregivers report participation in activities, such as coordination of care and
providing assistance with various activities of daily living (ADL) such as bathing, eating, and toileting, and instrumental activities of daily living (IADL), such as transportation, errands, and housework (AARP, 2015). This can add to additional stress caused by productivity loss, leave of absences, and/or reduced work hours, which in turn can lead to additional financial burden and loss of benefits (Collins & Swartz, 2011).

Ineffective coping, depression, and anxiety are three common themes that can lead to burden (Bove, Zakrisson, Midtgaard, Lomberg, & Overgaard, 2016; Figueiredo, Gabriel, Jacome, Cruz, & Marques, 2013; Iavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014; Jaracz et al., 2015). Jaracz et al. (2015) evaluated the effects of burden in caregivers of varied geographic and sociodemographic backgrounds in the post-acute phase of stroke and found that burden symptoms declined between three and twelve months post-stroke (16%). However, despite this decline, burden was found to be significant in the acute phase and continued up to five years post-stroke in caregivers of different sociodemographic backgrounds (29.5%) (Jaracz et al., 2015), highlighting the need for an intervention for effective coping and management of anxiety and depression in both short and long-term care. Figueiredo et al. (2013) and Iavarone et al. (2014) suggested that effective coping allows for a better transition into caregiving, as well as the adoption of healthy behaviors and emotional health, as the demands change. In turn, this will enhance a caregiver’s ability to strengthen their coping in both the early and later phases of caregiving.

The link between identification and management of caregiver-related stress to Primary Care is lacking in the community, leading to psychological distress in caregivers caused by poor utilization of caregiver-focused education programs (Bove et al., 2016; Jaracz et al., 2015). Belding and Kanis (2013), from the Central Massachusetts Agency on Aging (CMAA),
conducted a local community needs assessment and found that 42% of caregivers reported the need for assistance with daily tasks. The assessment concluded that 25% of caregivers face conflict, struggle with decision-making, and fail to recognize the impact of the stress on their health, while 28% of caregivers felt that education and support would be useful (Belding & Kanis, 2013). By 2030, the population of frail elders in the Central Massachusetts community is projected to rise from 17.8% to 28% (Belding & Kanis, 2013), which will impact caregivers who will continue to require community services and local support.

Bove et al. (2016) and Jaracz et al. (2015) highlighted the need for provider awareness and the acknowledgement of burden experienced by caregivers, as well as the incorporation of caregivers into the care plans of care recipients, in order to be able to provide education, care guidelines, and support. Bove et al. (2016) reported that caregiver participants sought information in both the early and late stages of chronic illness, which is crucial to the well-being and the unpredictable course of the caregiver. Identifying symptoms of caregiver burden is crucial so that the appropriate psychological and psychosocial interventions can be developed and used to improve health outcomes in both caregivers and care recipients alike (Del-Pino-Casado, Perex-Cruz, & Frias-Osuna, 2014). Using structured and tailored psychoeducational interventions can improve caregiver coping through cognitive restructuring, communication, decision-making, and problem solving assist in diminishing the level of stress experienced by family caregivers (Iavarone et al., 2014).

**Problem Statement**

The risk for burden among family caregivers who provide care to older adults with chronic illness is significant due, in part, to the devastating effects on the caregivers as evidenced by symptoms of psychological distress, depression, anxiety, social isolation, and poor quality of
life caused by ineffective coping strategies. Without awareness among providers and family caregivers of the potential for psychological and physical effects of burden, caregivers are likely to struggle with ineffective coping mechanisms leading to deterioration in their health and well-being (Carrasco et al., 2009; Etemadifer et al., 2014; Savundranayagam, Montgomery, Kosloski, & Little, 2010; Livingston et al., 2014; Sun et al., 2015; Won et al., 2008). The DNP student prepared, presented, and evaluated a Caregiver Toolkit to a Primary Care office and focused on the use of a psychoeducational intervention program in the community known as Powerful Tools for Caregivers (PTC). This program is an evidence-based caregiver-focused course and emphasizes the importance of caregiver health and wellness in order to be an effective caregiver (PTC, 2016). Creating a Caregiver Toolkit resource that included information on the PTC program and additional local community resources assisted in increasing awareness among Primary Care providers and family caregivers that can ultimately help to diminish the effects of burden experienced by family caregivers.

**Review of Literature**

**Methods**

A comprehensive search of the literature on interventions for caregiver burden included PubMed, Academic Search Premier, and Cumulative Index of Nursing and Allied Health Literature (CINAHL). The search yielded 319 results between 2005 and 2015. Search terms included *caregiver burden, psychoeducation, coping, and intervention* and recommended medical search (MeSH) terms included *burden of illness, family caregiver, chronic illness* and *coping skills*. Inclusion criteria included full text peer reviewed articles in English. Exclusion criteria included caregiver burden associated with pediatrics, acute exacerbations associated with chronic illnesses, and mental health conditions other than dementia.
Results

A total of six articles were used in the literature review based on the positive outcomes in caregiver health that were demonstrated in the findings in interventions up to two-years post-intervention. Selection criteria included literature that focused on psychological and psychosocial training interventions that targeted caregiver burden and ineffective coping as evidenced by psychological distress, depression, anxiety, social isolation, and poor quality of life. The John Hopkins Nursing Evidence-Based (JHNEBP) Evidence Rating Scale was used to rate the strength and quality of evidence of the literature and a clinical practice guideline (Whitehouse, Dearholt, Poe, Pugh, & White, 2007). Literature included in the review is two randomized control trials (RCT) and an experimental study that are a level I grade A, two quasi-experimental studies that are a level II grade A, and one RCT that is a level I grade B.

All six studies identified challenges that caregivers face in their role as primary caretakers and focused on interventions that had a significant outcome in their well-being due to proper self-care practices. The psychoeducational and psychosocial training interventions assisted in minimizing symptoms of anxiety, depression, and burden brought on by daily caregiving tasks. Each study used a structured curriculum that allowed for flexibility in order to be able to tailor education and support given to caregivers. Four studies included psychoeducational interventions conducted by a counselor, nurse, or psychiatrist, and two used an interdisciplinary approach that involves multiple health care professionals.

Psychoeducational, psychosocial training, and interdisciplinary approach interventions

The use of psychoeducational and psychosocial training interventions for caregivers managing the care of chronically ill family members has positively correlated with statistically
significant results (Carrasco et al., 2009; Etemadifer et al., 2014; Savundranayagam et al., 2010; Livingston et al., 2014; Sun et al., 2015; Won et al., 2008). In the literature review, all studies incorporated some form of psychoeducation and coping skills training and demonstrated positive outcomes in health and well-being in caregivers through the use of structured interventions and follow up care. More specifically, Won et al. (2008) and Savundranayagam et al. (2010) assessed the effectiveness of the Powerful Tools for Caregivers (PTC) program, an evidence-based psychoeducational training caregiver course, that has a goal of focusing on coping, problem solving, and enhancing support. In an experimental study, Won et al. (2008) evaluated self-efficacy in caregivers who voluntarily participated in the PTC program; caregivers who participated in the caregiver course were more likely to have improved self-care practices, coping, problem solving, and well-being. Improved caregiver health was more significant in caregivers who were less than 65 years of age and had a college degree, meaning that a higher level of education was positively correlated with improvements in health status (Won et al., 2008). A unique quality of this study was that it was a real world program and was not conducted for research and caregivers were not recruited, which led to statistically significant results and compliance with the PTC program (Won et al., 2008, p. 6).

Similarly, Savundranayagum et al. (2008) added to the literature by Won et al. (2008) by enhancing the usefulness of the PTC program when three types of burden were measured (i.e., stress burden, objective burden, and relationship burden). In the findings, there was a significant decrease in objective burden as well as psychological distress in caregivers in the intervention group versus caregivers in the control group (Savundranayagum et al., 2008). There was not as much of an effect on the care recipient-caregiver relationship as evidenced by a minimal change in relationship burden (Savundranayagum et al., 2008). However, a positive quality of the PTC
program is the use of stress management and relaxation training in all six sessions, which can assist in enhancing relationship burden experienced by care recipient-caregiver dyads over time (Savundranayagum et al., 2008; Won et al., 2008).

In two additional studies, Livingston et al. (2014) and Carrasco et al. (2009) both conducted separate RCTs at different mental health facilities for caregivers of care recipients with dementia. Both psychological and psychosocial training interventions focused on coping, relaxation, skills training, planning, and communication skills associated with dementia in care recipients.

Livingston et al. (2014) conducted a parallel group, superiority, single blind RCT with an intervention (START) (N = 173) and treatment as usual (TAU) groups (N = 87); caregivers had varied sociodemographic and clinical characteristics and were recruited from different service locations. The program took place during the early onset of disease, which can help caregivers to adapt their role as dementia worsens. The structured psychological START (STrAtegies for RelaTives) intervention included eight individual sessions that focused on stress and well-being, reasons for behavior recognition, restructuring coping, communication, planning for the future, use of pleasant events, and use of new skills for the future (Livingston et al., 2014). The Hospital Anxiety and Depression Scale total Score (HADS-T) was used to evaluate primary caregivers. At two years post-intervention, caregivers in the START intervention group had significantly decreased depressive and anxiety symptoms and level of burden (i.e., mean difference −2.58 points, 95% CI −4.26 to −0.90; p=0.003) and caregivers in TAU were found to be seven times more likely to experience depression (Livingston et al., 2014). Although health care costs accrued over the course of the disease process of worsening dementia, this type of psychological intervention was both cost-effective and beneficial based on the outcomes in
family caregivers (Livingston et al., 2014). A benefit of research by Livingston et al. was that the long-term evaluation over two years demonstrated that caregivers in the intervention group experienced an increase in quality of life and use of coping strategies, whereas other studies in the literature review were only evaluated at three and six months post-intervention. Additionally, this intervention was provided in the home setting and showed a positive change in anxiety and depression as evidenced by a change in caregiver mood and quality of life (Livingston et al., 2014). The ability to participate in a home or community-based program outside of an office or hospital setting is a positive program aspect for caregivers who find participation difficult due to the lack of resources and time management issues.

Carrasco et al. (2009) conducted a multicenter, prospective RCT with an intervention (IG) (N = 55) and control groups (CG) (N = 60). The psychological intervention program (PIP) for the IG included eight 90-minute sessions over four months. Education focused on ways to diminish stress through cognitive behavioral restructuring and 91.7% of caregivers in the PIP participated in all sessions (Carrasco et al., 2009). A significant decrease in burden was identified in the IG that demonstrated that caregivers in the IG with PIP experienced symptoms that were lowered to mild burden (i.e., mean score of 54) with an 8.1 point decrease and caregivers in the CG continued to experience symptoms that were considered severe burden (i.e., mean score of 60.5) with a 2.1 point increase on the Zarit burden scale (Carrasco et al., 2009). A reduction in burden in the IG with PIP led to an enhanced quality of life and decreased psychiatric morbidity in caregiver participants (Carrasco et al., 2009). A decrease in both Primary Care and specialist visits was evidenced in the IG group with PIP. Also noted in the findings of this study was the reduction in burden in caregivers who were presently working with a medical team at a mental health facility, which highlights the importance of involvement with
mental health services for caregivers who care for dependents with dementia (Carrasco et al., 2009).

As discussed previously, research by Livingston et al. (2014) and Carrasco et al. (2009) found a significant decrease in burden measured by the two different burden scales as evidenced by an evaluation of scores pre and post-intervention, whereas caregivers in control groups continued to experience a significant level of burden if provided standard care only. Furthermore, Carrasco et al. found that caregivers in the IG had decreased psychiatric morbidity and a lower number of specialist and Primary Care visits with the utilization of community resources, while caregivers in the CG only had a decrease in specialist visits; this further strengthens the validity of this type of psychoeducation and psychosocial training intervention. Livingston et al. and Carrasco et al. both support that a decrease in burden positively correlates with outcomes in psychiatric and caregiver health and well-being. Recruiting caregivers from multiple mental health facilities proved to be effective in the outcomes of caregivers who participated in intervention groups and assisted in minimizing burden symptoms and optimized coping skills. Both studies demonstrated that the use of therapists in a structured psychoeducational intervention is beneficial to health outcomes in caregivers. Future studies should emphasize the importance of long-term evaluation of interventions that can strengthen their confidence in care and assist family caregivers in adapting to their role as caregiving demands increase with disease progression.

Etemadifer et al. (2014) and Sun et al. (2015) conducted studies that utilized multiple health care professionals as a team effort, which were noted to be a valuable component to their psychoeducational interventions that combined both education and support for caregivers to focus on managing stress and improving coping strategies. Overall, the level of burden and
psychological distress was drastically decreased and the physical and social quality of life and skill preparedness increased by participation and was followed for up to three months post-intervention. Additionally, both Etemadifar et al. and Sun et al. claim that the use of multiple health care professionals in the management burden was significant and promotes self-care, effective coping, and proper use of time management.

Etemadifar et al. (2014) compared two groups an intervention (N = 50) and control group (N = 50) with caregiver characteristics that included 38.1% daughters, 28.6% spouses, 19% sons, 9.6% siblings, 4.7% parents; 76.2% married and 54.8% housekeepers. A significant change in burden scores was evidenced by a decrease in Zarit Burden Interview (ZBI) scores from severe burden at 57.28 to mild burden 36.15 in the intervention group whereas burden levels remained elevated at pre and post-evaluation of burden in the control group (Etemadifar et al., 2014).

Sun et al. (2015) conducted a two-group prospective, sequential, quasi-experimental study with an intervention group (N = 191) and control group (N = 153). Participants included caregivers who cared for family members with lung cancer (i.e., stages I-IV) in Southern California; caregivers had at least one chronic illness with additional characteristics that included 60.6% women, 23.6% worked >32 hours/week; 63.8% women, and 34.4% worked >32 hours/week (Sun et al., 2015). The program consisted of four education classes broken down into four quality of life domains (i.e., physical, psychological, social, and spiritual well-being). Both groups of caregivers were evaluated using the City of Hope QOL tool and the Montgomery Caregiver Burden Scale and the control group only received interdisciplinary palliative care. Results from the intervention group demonstrated a positive change in social quality of life (z-score 6.48 vs 6.0) and psychological distress (z-score 4.20 vs 4.61) when compared to the control group (Sun et al., 2015). Burden was diminished in the intervention group as evidenced by less
objective (33%) and subjective reported stress (13% vs 24%) (Sun et al., 2015). It was noted that self-care plans for caregivers in the intervention group further supported their needs for preparedness for the future and provided a clear pathway that supports physical, psychological, social, and spiritual quality of life domains (Sun et al., 2015).

Limitations in the literature are minimal generalizability to other populations, small sample size due to the inability of obtaining an appropriate sample with burden, short-term interventions, and attrition rates due to health, death, or institutionalization (Carrasco et al., 2009; Etemadifar et al., 2014; Livingston et al., 2014; Savundranayagam et al., 2010; Sun et al., 2015; Won et al., 2010). Additionally, convenience sampling and nonrandomized design may impact caregiver outcomes as well as bias the intervention effect for management of caregiver burden (Savundranayagam et al., 2010; Sun et al., 2015; Won et al., 2010).

Recommendations for initiation of psychoeducational and psychosocial training programs for caregivers is generally recommended at the onset of care (Savundranayagam et al., 2010; Sun et al., 2015), however, it is often during times of elevated stress, initiated by limited resources and both professional and nonprofessional support, when symptoms of psychological distress, anxiety, depression, and social isolation are evident. Symptoms of caregiver burden lead to higher caregiver demands and the interventions are shifted to focus on minimizing the effects of burden on health instead of promoting a sense of well-being preventing the onset of burden. Therefore, as discussed previously, awareness among Primary Care providers for referral of community resources, as well as incorporating caregivers into the care plan of chronically ill elders, is essential for caregiver health and optimal coping (Etemadifer et al., 2014; Sun et al., 2015). Recommendations from the literature encourage the use of structured psychoeducational and psychosocial training interventions early in the disease process as well as long-term contact
with providers throughout the disease trajectory to improve caregiver health outcomes that assist
caregivers with coping skills and provide support (Carrasco et al., 2009; Etemadifar et al., 2014;
Livingston et al., 2014; Sun et al., 2015).

**Theoretical Framework**

Lazarus and Folkman’s Transactional Theory of Stress and Coping is a theoretical
framework that has been used to identify and manage caregiver stress and will be used to guide
the DNP-led project (Lazarus & Folkman, 1984). The theoretical framework is provided in
Appendix A. This theory focuses on psychological responses of coping with stressful events that
occur in ones life that may or may not be out of their control (Lazarus & Folkman, 1984). Since
chronic illnesses are progressive and often debilitating in nature, it is essential to focus on
altering the stress response in caregivers who provide emotional and physical support to these
individuals to improve quality of life. Identifying caregiver burden at the provider level is crucial
to prevent the long-term effects that can impact the caregiver emotionally, physically, socially,
and financially. In this theory, two factors that contribute to stress are the individuals’
relationship with the environment and two appraisals that aid in adaptive coping (Lazarus &
Folkman, 1984). Factors that affect the person-environment include life events, values, beliefs,
cultural factors, and social networks and support (Lazarus & Folkman, 1984). Primary and
secondary appraisals are used as the individual identifies how they perceive a threat or challenge
and transform their stress and coping response as they adapt to the environment (Lazarus &
Folkman, 1984). Using this theory to guide the PTC program will assist caregivers to identify the
cause of the stress. It will also help Primary Care providers and family caregivers to recognize
how stress can relates to the high demands of caregiving and lack of support (primary appraisal)
that leads to burden and restructuring problems and emotion-focused coping strategies
(secondary appraisal) that will ultimately improve their functioning, support system, and role as a caregiver through participation in community-based support programs (Lazarus & Folkman, 1984).

**Project Design and Methods**

**Design and Methods**

An integrative review of the literature helped to guide the DNP project and included the development, presentation, and three-month post-education evaluation of a Caregiver Toolkit for Primary Care. The DNP student first became certified as a Class Leader using a train the trainer approach to conduct the PTC program, along with a Caregiver specialist/Master Trainer, and then a Caregiver Toolkit for presentation was created. The Caregiver Toolkit included a description of the PTC program, a post-intervention survey that assisted in identify ways to decrease the gap in care between Primary Care providers and referral of community resources, and local contacts for support. Data was then collected from providers’ in a three-month post-education intervention survey that assessed the use of the Caregiver Toolkit in Primary Care.

**Target Population, Setting, and Resources**

The target population included both Primary Care providers and family caregivers of chronically ill family members. The population of caregivers for the PTC program in Central Massachusetts included designated primary family caregivers who provide at least four hours of caregiving tasks and/or responsibilities each day. A caregiver is identified as one who assists in managing the care of an adult who is 65 years of age or older with at least one or more diagnosed chronic condition.

Central Massachusetts is the geographical area that was chosen to implement the project due to the self-identified need for caregiver support and resources as evidenced by the
community needs assessment report discussed previously (Belding & Kanis, 2013). The demographic of individuals who are at least 60 years of age who reside in Central Massachusetts is 150,280 (11.8%); this potentially vulnerable population is projected to increase to 201,326 (12.3%) by 2020 and could impact the health of caregivers and care recipients alike (Belding & Kanis, 2013). Residents in this community are primarily Caucasian or White; minority groups (Black, Hispanic, Asian, Native American, and Pacific Islanders) constitute 7% of the population and are expected to double from 2010 to 2025 (Belding & Kanis, 2013). In comparing employment status in Central Massachusetts, the majority of individuals older than 60 years of age are retired in small (64.9%) and large (65.8%) communities, thus adding financial strain to the role of caregiving (Belding & Kanis, 2013). Health perception of this group is identified as excellent, good, fair, or poor and was rated as 25.3%, 51.7%, 19.7%, and 2.2% respectively (Belding & Kanis, 2013). In the elderly population (i.e., 75 years of age or older), the need for community-based services is projected to triple for Asians and Latinos and double for Blacks (Belding & Kanis, 2013), which highlights the need to identify caregiver burden and increase the awareness among Primary Care providers of community resources and interventions.

Both Elder Services of Worcester Area (ESWA) and Trivalley provide a wide range of services to individuals and families in Central Massachusetts that include home-based services, caregiver and family support, companionship, and transportation, and community-based education to name a few. Both agencies receive referrals from the Central Massachusetts Agency on Aging (CMAA), Primary Care offices, home care facilitates, hospitals, and self-referrals. However, the growing concern of poor caregiver health outcomes is a key component that could assist in diminishing this gap by educating Primary Care providers who can assess and refer caregivers to psychosocial training interventions, such as the PTC program.
Multiple stakeholders were included in the DNP project. Stakeholders included a Caregiver Specialist/Master Trainer from ESWA for the PTC program and a nurse case manager at the Reliant Medical Group practice site in Spencer, Massachusetts where the Caregiver Toolkit was dispersed and assessed for its use in Primary Care. The role of the Caregiver Specialist/Master Trainer was to co-leading with the caregiver training and the role of the nurse case manager was to assist with implementation of the Caregiver Toolkit at the Reliant Medical Group practice site. The stakeholder support and letter agreements are provided in Appendix B and C. Additional stakeholders included a total of seven providers at the Reliant Medical Group practice site.

Organizational Analysis of Practice Site

The Reliant Medical Group practice site is a multidisciplinary practice with multiple providers. Such providers include three physicians and five nurse practitioners. There is one office manager, one nurse case manager, six staff nurses, six medical assistants, and several office staff members. Prior to implementation of the education intervention of the Caregiver Toolkit, the practice did not offer information regarding caregiver support and education provided in the PTC program; only general referrals are made to Elder Services of Worcester Area (ESWA) and/or Trivalley that focus mainly on the care recipient. The nurse case manager at the practice site presently assists patients and families in setting up outpatient and home-based services with an overall goal of reducing hospitalizations and readmission rates. The plan for the DNP project was to create a Caregiver Toolkit to present to the Primary Care providers at the Reliant Medical Group practice site, which assisted in educating health care professionals and family caregivers on the importance of caregiver wellness and increased the awareness of community resources by participating in programs such as the PTC program. An office visit
(e.g., physical examination, follow up, and/or episodic visit for a care recipient and/or caregiver) is an ideal time to be able to identify caregivers and discuss concerns related to the caregiving role and community resources that can optimize their health as an individual and as a caregiver. The outpatient practice setting was chosen to be able to educate providers who have long-term contact with primary family caregivers who often provide daily care to chronically ill family members and can experience symptoms of caregiver burden, as noted at length above, if the condition is not identified and managed appropriately.

**Toolkit Implementation**

**Goals and Objectives**

Goals are used as broad statements for future outcomes that provide the framework of a project whereas objectives are measurable and time-limited actions that assist to move the project to complete designated goals (Zaccagnini & White, 2014). Goals and objectives for the Caregiver Toolkit presentation and post-education evaluation of the PTC program to assist in increasing awareness in Primary Care are reviewed in the following subsequent sections.

**Pre-toolkit preparation**

*Goal 1. Training.* First, the DNP student decided with the Master Trainer from Elder Services of Worcester Area (ESWA) on a timeframe and location for the PTC program, which was held at the Rutland Senior Center in Rutland, Massachusetts on six consecutive Tuesdays on September 20th and 27th and October 4th, 11th, 18th, and 25th of 2016. Next, the DNP student participated in a two-day training (i.e., 8 hours/day) to become a Class Leader for the PTC program in Brockton, Massachusetts on September 7th and 8th of 2016. The purpose of the training was for the DNP student to co-lead the PTC program to gain a better understanding and
knowledge on the impact of the intervention and the importance promoting caregiver health to discuss with Primary Care providers during the Caregiver Toolkit presentation.

*Goal 2. Caregiver education.* For the development of the Caregiver Toolkit, the DNP student and Master Trainer from ESWA conducted the caregiver course in six weekly 90-minute sessions that were divided into different education topics pertaining to improving caregiver health. Education topics included self-care, identifying and managing stress, communicating caregiver needs and concerns, needs, and concerns, effective communication with care recipients, understanding caregiver emotions, and navigating decision-making in challenging situations (PTC, 2016). A survey was created by the DNP student to assess the impact of the PTC program on caregiver burden that identified ways to diminish the gap in care between Primary Care providers and burden experienced by family caregivers and was completed anonymously. The survey is provided in Appendix D. A Health Insurance Portability and Accountability Act (HIPAA) form was signed at the conclusion of the course to protect health information of all caregiver participants prior to completing the post-intervention survey.

**Toolkit development**

*Goal 3: Appraise, direct, and evaluate.* After co-leading the PTC program, a Caregiver Toolkit was created by the DNP student and then dispersed to six providers and a nurse case manager at the Reliant Medical Group practice site in Spencer, Massachusetts. The Caregiver Toolkit included a course overview, goals, and objectives of the PTC program, a post-evaluation through SurveyMonkey of burden and the impact caregivers felt that the course would have had if Primary Care providers would have been aware of the intervention, and local community resources and contacts currently provided through ESWA and Trivalley.

**Presentation**
Goal 4: Toolkit presentation. The DNP student conducted a thirty-minute presentation on October 19th 2016 after the Caregiver Toolkit was created in a PowerPoint presentation format. The PowerPoint presentation is provided in Appendix E. The goal of this meeting was to educate the providers, along with the nurse case manager and mentor at the Reliant Medical Group practice site, on the contents in the Caregiver Toolkit. This allowed providers to gain an understanding of the positive impact of the PTC program on caregiver health and how this is a useful community resource. The overall goal and purpose was for providers to incorporate the Caregiver Toolkit into practice so that both providers and caregivers can be aware of community resources to prevent caregiver-related stress and burden and assist caregivers as they transition throughout the caregiving role.

Goal 5: Evaluate outcomes. The DNP student created a survey through SurveyMonkey and printed and dispersed a three-month post-education intervention of the Caregiver Toolkit to evaluate the use and effectiveness at the practice site. The survey is provided in Appendix F. At this time, the Caregiver Toolkit’s use for the assessment, management, and referral of community resources to manage caregiver stress and burden in family caregivers was only evaluated at the Reliant Medical Group practice site.

Ethics and Human Subjects Protection

The University of Massachusetts Amherst Internal Review Board (IRB) approval was granted after the project proposal was approved. All participants in the DNP project were protected by the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which protects the health information of patients (Modifications to the HIPAA Privacy, Security, Enforcement, and Breach Notification Rules, 2013). Additionally, the DNP student and practice personnel who carefully conducted this project followed the Standards of Care for practice in a
primary care office. As part of the evaluation process, all information that was collected was aggregated data from the participants and did not include any potential patient identifiers. Participant confidentiality was assured by making sure that all hand written post-intervention surveys from family caregivers participating in the PTC program was completed anonymously and collected solely for the purpose of promoting caregivers health after completion of the course by increasing awareness of the intervention among providers at Reliant Medical Group in Spencer, Massachusetts. The informed consent form is provided in Appendix G. The nurse case manager and providers also completed a written three-month post-education evaluation survey anonymously.

**Results**

**Outcomes**

The outcomes from the post-education intervention and presentation survey to providers at a Reliant Medical Group practice site are numerous. The Caregiver Toolkit was presented to six of the eight providers (e.g., physicians and nurse practitioners [NP]) and one nurse case manager. Overall the data presented in the Caregiver Toolkit and discussion of the PTC program was well received. The toolkit allowed providers to understand the positive impact of the PTC program on caregiver health and how the intervention is a useful community resource. Feedback from presentation participants included that they had not heard of and/or had exposure to the caregiver intervention, they felt that it would be beneficial to caregivers’ individual health, and recognized the positive impact the PTC program has on the health of caregivers and care recipients alike.

At the time of three-month post-education and presentation evaluation, a significant amount of positive feedback was given that highlights the importance of the usefulness of the
PTC program in the community for family caregivers. There were six out of seven participants in the seven-question survey from the Caregiver Toolkit presentation; one participant was not available at the time that the survey was completed. All six respondents (100%) felt that the Caregiver Toolkit increased their awareness and need for identification of caregiver burden. A total of five of six respondents (83.3%) felt that they were either referring more frequently to Elder Services of Worcester Area (ESWA) and/or Trivalley or could do it more often and one of six respondents (16.7%) felt that their comfort level for discussion depended on the relationship with the patient and/or caregiver. A total of five of six respondents (83.3%) felt more knowledgeable and comfortable discussing the use of the PTC program in the community with patients and their caregivers and one of six respondents (16.7%) felt that their comfort level for discussion of the Caregiver Toolkit depended on the relationship with the patient and/or caregiver. A total of five of six respondents (83.3%) felt that they were more conscientious with identifying caregiver burden in caregivers when evaluating patients with single or multiple chronic condition and one of six respondents (16.7%) felt that their ability to identify symptoms of caregiver burden depended on the patient and/or caregiver. A total of three of six respondents (50%) felt that caregivers were very receptive to the Caregiver Toolkit, PTC program, and community resources while the three remaining respondents (50%) felt that caregivers were somewhat interested in the contents provided in the Caregiver Toolkit. All six respondents felt that additional information was not necessary to change the Caregiver Toolkit for Primary Care. There were no additional handwritten responses for the final question regarding making changes to the Caregiver Toolkit that provided many local resources and contacts in Central Massachusetts for family caregivers.
As noted in the three-month post-education survey results above, there was very minimal negative feedback from participants’. The only setback was identified when participants’ reported that discussion of the PTC program and referral to community resources when providers felt that it depended on the patient and/or caregiver and their relationship. Interestingly, in the outcomes from caregiver respondents who participated in the six-week PTC program prior to the development and presentation of the Caregiver Toolkit, caregivers felt that participation in the intervention improved communication with health care professionals, increased the ability to identify nonprofessional and professional assistance, recommended more advertisement and availability of course, and wished they had heard of the program earlier in the caregiving process. Regardless of the relationship between the patient-provider and/or the caregiver-provider, it is the opinion of the DNP student that educating health care professionals and family caregivers in outpatient practice settings will improve awareness and the use of the PTC program and other community-based programs that will positively impact health outcomes of caregivers and care recipients based on the findings discussed above.

Discussion

Facilitators and Barriers

Both facilitators and barriers exist with the sustainability of a community-based psychoeducational and psychosocial training program for caregivers who experience symptoms of caregiver-related stress. There has been a significant movement towards supporting caregivers in managing the care of chronic conditions, not only to assist in the care of care dependents, but also to identify ways to improve their personal health (Bookman et al., 2008). Many organizations are available that support caregivers on national, state, and local levels to increase the availability of educational and supportive interventions. Therefore, increasing awareness of
community interventions and supportive networks among providers in Primary Care can assist in diminishing the gap in care that currently exists (Bove et al., 2016; Etemadifar et al. 2014; Jaracz et al., 2015; Sun et al., 2015). Although the PTC program has been available twelve years, five out of the six providers were unaware of the community resource (PTC, 2016). All providers were unaware of the positive impact it has on caregivers and how well it was received in the community. An on-site nurse case manager who assists with caregiver outreach, was beneficial to the DNP project since the goal was to increase awareness of the PTC program and use of community resources. What is especially unique to the Central Massachusetts PTC program is that ESWA presently offers respite care covered through the Family Caregiver Support Program (FCSP) and/or insurance that can assist in improving caregiver support and compliance with the course. Potential barriers can include the loss of contact or inability to appropriately reach a significant number of caregivers who experience psychological distress, office visit time constraints, and specific time and availability of the PTC program since the course is currently offered three to four times each year. Additionally, the DNP project offered a post-education survey to a small sample at a single site that evaluated qualitative data. However, the data retrieved from the DNP project is significant and positively correlates with outcomes of similar caregiver education programs that are presently noted in the literature to assist in alleviating caregiver-related stress associated with burden over the trajectory of chronic illness management.

**Future Recommendations**

As discussed above, support in both the early and late phases of caregiving are equally important. As noted in a clinical practice guideline provided through the National Guideline Clearinghouse (NGC) (2012), one of the six major recommendations with the highest level of evidence (i.e., level I) and graded as I-IV, focuses on caregivers’ physical and mental health
status. With this recommendation, health perception should be evaluated, health conditions (e.g., anxiety, depression, and/or burden) should be identified and managed, and self-care activities for caregivers to develop new skills, coping strategies, competencies, and improve relationships and communication (National Guideline Clearinghouse [NGC], 2012). The clinical practice guideline not only supports the basis of the evidence-based practice PTC program, but it also provides a foundation for implementation of a Caregiver Toolkit in outpatient Primary Care practices to emphasize the importance of caregiver wellness. Assisting caregivers to develop coping strategies, effective communication and time management skills, self-care, and create communities via support groups and provider awareness can lead to positive health outcomes and diminish the effects of burden. Based on the outcomes of the three-month post-education intervention survey, it is the opinion of the DNP student that the Caregiver Toolkit would likely be reciprocal in other outpatient practice settings since it was so well received by all of the providers and the nurse case manager.

There are multiple studies related specifically to the PTC program, however limited data exists on the long-term effects of caregiver-focused wellness education programs since there have only been short-term evaluations on their effect on family caregivers (Won et al., 2008 & Savundranayagam et al., 2010). By continuing to increase awareness of the PTC program that can be included in a Caregiver Toolkit resource in outpatient practice settings, communication and patient-caregiver and family caregiver-provider relationships can be strengthened, thereby improving the health and support provided to caregivers. An additional tool that has been used in studies to evaluate caregiver burden and would be beneficial to assist in the diagnosis of caregiver burden may include the use of the Zarit Burden Interview (ZBI) or one of the other many screening tools that evaluate caregivers perceived health, functioning, coping, and support
(Carrasco et al., 2009; Etemadifer et al.; 2014, Livingston et al., 2014; Savundranayagam et al., 2010; Won et al., 2010). Other recommendations may also include coding caregiver burden with ICD-10 codes to be able to follow caregivers longitudinally that are affiliated in a Primary Care practice and participate in community-based programs and support groups.

**Conclusion**

The effects of caregiver burden on family caregivers are detrimental to one’s health without early identification and use of community resources that assist to relieve depression, anxiety, and social isolation by improving coping strategies (Bove et al., 2016; Figueiredo et al., 2013; Iavarone et al., 2014; Jaracz et al., 2015). Increasing community awareness among Primary Care providers (e.g., physicians, NP, and physician assistants [PA]) and other health care professionals (e.g., nurse case managers, registered nurses [RN], and social workers) on the availability of the PTC program in the community and use of a Caregiver Toolkit at outpatient practice sites can lead to the early identification of caregiver burden and service referral. In turn, this will help family caregivers to obtain community-based services to improve personal health while caring for chronically ill and dependent elders. As discussed at length above, participation and use of the Caregiver Toolkit at Reliant Medical Group in Central Massachusetts increased awareness of community resources for caregivers and provided evidence-based research and findings from a three-month post-education intervention survey that strengthened the importance of assessing and incorporating caregiver health into the management of chronically ill dependents. Therefore, increasing the use of a Caregiver Toolkit and the PTC program in the community setting can assist primary caregivers by linking them with community resources, health care professionals, and other family caregivers. Ultimately, this in turn can help to
diminish the gap in care that exists through lack of awareness and identification and management of caregiver burden in Primary Care.
References


Health and Human Services Department. (2013). Modifications to the HIPPA Privacy, Security, Enforcement, and Breach Notification Rules Under the Health Information Technology for Economic and Clinical Health Act and the Genetic Information Nondiscrimination Act; Other Modifications to the HIPPA Rules. Retrieved from


Appendix A
Theoretical Framework: Lazarus and Folkman’s Transactional Theory of Stress and Coping

Lazarus and Folkman, 1984
Appendix B
Stakeholder Agreement: Elder Services of Worcester Area (ESWA), PTC Intervention

Appendix C
Stakeholder Letter: Reliant Medical Group, Spencer, Massachusetts

[Date] 4/26/11

To Whom It May Concern:

I am the Director of the DNP Program at the University of Massachusetts, Amherst, College of Nursing. I am writing this letter on behalf of Ashley Cohen, your student preceptor. Your student is planning to complete the pinnacle requirement for the Degree, a DNP Capstone Project, in your facility. Your student will be designing, implementing, and evaluating the impact of translating a programmatic intervention into your practice or setting. As these projects are considered performance improvement, quality improvement, or program evaluation projects and not research studies, the University does not require Institutional Review Board (IRB) permission for this student to actualize the project as outlined by the student and approved by preceptor/s within your facility. I am using this letter as a “Key Stakeholder” commitment letter for the student to use in the DNP Capstone Project Proposal. A Graduate faculty member of the College of Nursing will also be working directly with your student as Chair of the DNP Capstone Project Committee.

Thank you in advance for allowing this student to actualize the DNP Capstone Project in your facility. If you have any questions, please call me at 413-545-5089 or email paselton@nursing.umass.edu.

Key Stakeholder Signature: [Signature]
Date: 4/26/11

Student Signature: [Signature]
Date: 4/26/11

Sincerely,

Pamela Alston

Pamela Aselton, PhD, FNP-BC
Associate Professor
Director DNP Program

Appendix D
Survey for Caregivers Post-Powerful Tools for Caregivers (PTC) Intervention*

<table>
<thead>
<tr>
<th>Post-Powerful Tools for Caregivers (PTC) course Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you think the Powerful Tools for Caregivers (PTC) course has improved your health as a caregiver?</td>
</tr>
<tr>
<td>□ Yes</td>
</tr>
<tr>
<td>□ No</td>
</tr>
<tr>
<td>□ Somewhat</td>
</tr>
<tr>
<td>□ It could be better</td>
</tr>
<tr>
<td>2. Do you think that you are able to use coping strategies more effectively?</td>
</tr>
<tr>
<td>□ Yes</td>
</tr>
<tr>
<td>□ No</td>
</tr>
<tr>
<td>□ Somewhat</td>
</tr>
<tr>
<td>□ I'm still having a difficult time</td>
</tr>
<tr>
<td>3. Are you now able to identify ways to reduce stress and discuss any concerns with your physician/health care provider if necessary?</td>
</tr>
<tr>
<td>□ Yes</td>
</tr>
<tr>
<td>□ Not at all</td>
</tr>
<tr>
<td>□ Somewhat</td>
</tr>
<tr>
<td>□ I could benefit from additional education</td>
</tr>
<tr>
<td>4. Are you able to communicate better (about stress, coping, obtaining resources) with your loved one or friend and physician/health care provider more easily?</td>
</tr>
<tr>
<td>□ Yes</td>
</tr>
<tr>
<td>□ No</td>
</tr>
<tr>
<td>□ Sometimes</td>
</tr>
<tr>
<td>□ It depends on the provider</td>
</tr>
</tbody>
</table>
5. Are you able to identify additional support (family, friends, physician/health care professional)?
   - Yes
   - No
   - Somewhat
   - I'm still having a hard time

6. Do you think it would have been helpful for your physician/health care provider to be aware of the Powerful Tools for Caregivers (PTC) course to be able to discuss the course, effect of elevated stress associated with caregiving, and to help increase awareness of this and similar programs in the community?
   - Maybe
   - No
   - I wish I would have known about this program earlier
   - I'm not comfortable talking about this with my physician

7. What suggestions do you have to increase awareness of the Powerful Tools for Caregivers (PTC) course in your community?

*Created by DNP student*
Appendix E
PowerPoint Presentation Overview
What is Powerful Tools for Caregivers?

- A nationally recognized, evidence-based caregiver course
- Helps caregivers to develop self-care tools that focus on individual health and can alleviate stress and burden and symptoms of depression, guilt, and anger
- The course has been offered for 12 years in 36 states and has reached over 80,000 caregivers
- Currently offered 3-4 times/year
- Based off of the Chronic Disease Self Management Program

Powerful Tools for Caregivers (2016)
**Goals: Caregiver Toolkit**

- Increase awareness of the Powerful Tools for Caregivers course
- Decrease the effects of caregiver-related stress
- Improve caregiver health, wellness, and coping
- Increase the use of community resources
- Improve provider-caregiver and caregiver-care recipient communication
- Enhance support systems for caregivers
Powerful Tools for Caregivers

- Course content is broken down into six 90-minute weekly sessions
- Uses brainstorming activities to identify and reduce stress; changes thought processes when communicating and teaches how to communicate effectively with family members and health care professions; changes negative to positive self-talk; helps with decision-making, understanding emotions, and setting short-term goals by creating action plans to enhance self-care

Powerful Tools for Caregivers (2016)
Toolkit Contents

- Powerful Tools for Caregivers pamphlet
- Description of course
- Information for the Family Caregiver Support Program
- Caregiver Guide specific to caregivers in Central MA
- Community contacts and agencies
  - Elder Services of Worcester Area (ESWA)
  - Trivalley
Powerful Tools for Caregivers

- **Week 1:** Taking care of you
- **Week 2:** Identifying and reducing person stress
- **Week 3:** Communicating feelings, needs, and concerns
- **Week 4:** Communicating in challenging situations
- **Week 5:** Learning from emotions
- **Week 6:** Mastering caregiving decisions
Caregiver Survey

- Improved self-care and caregiver health
- Adapted coping strategies and able to use them more appropriately
- Can identify ways to decrease stress
- Improved communication with family and health care professionals
- Identify nonprofessional/professional support and resources
- Wished they had known about Powerful Tools earlier in the caregiving process and that their PCP would have been aware of the program
- Recommended more advertisement and availability
### Post-presentation of Caregiver Toolkit use in Primary Care

1. Do you feel that the Caregiver Toolkit has increased your awareness and need for identification of caregiver burden?
   - Yes
   - No
   - Somewhat
   - I could talk about it more with patients and their caregivers

2. Do you find that you are referring caregivers to Elder Services of Worcester Area (ESWA) and/or Trivaley more frequently?
   - Yes
   - No
   - I could do it more often

3. Do you feel more knowledgeable and comfortable discussing use of the Powerful Tools for Caregivers (PTC) course with patients and their caregivers?
   - Yes
   - No
   - Somewhat
   - It depends on the patient and/or caregiver

4. Are you more contented with identifying caregiver burden when you are evaluating patients with single or multiple complex chronic conditions?
   - Yes
   - No
   - Sometimes
   - It depends on the patient

*Appendix F*
Survey for Primary Care Providers’ Post-Presentation of Caregiver Toolkit*
5. How receptive do you feel family caregivers are when you discuss the Caregiver Toolkit with them along with the availability of the Powerful Tools for Caregivers (PTC) course in the community?
   - Very receptive to services
   - Somewhat interested
   - They ask additional questions
   - Not receptive at all

6. Do you feel that any additional information should be added to the Caregiver Toolkit for Family Practice?
   - Yes
   - No

7. Place suggestions for the Caregiver Toolkit here:

*Created by DNP student
Appendix G
Informed Consent Form: Focus Group Participants

University of Massachusetts, Amherst – College of Nursing

This Informed Consent Form is for participants who are enrolled in the Powerful Tool for Caregivers (PTC) group through Elder Services of Worcester Area (ESWA) at the Rutland Senior Center in Rutland, Massachusetts on September 13th, 20th, 27th and October 4th, 11th, and 18th of 2016. Participants will be evaluated with a questionnaire after completing the course on the impact of the PTC intervention on their level of caregiver stress and burden to help identify ways to increase community awareness of burden and to improve use of caregiver education and support among Primary Care providers and family caregivers.

This Informed Consent Form has two parts:
- Information Sheet (to share information about the project with you)
- Certificate of Consent (for signatures if you choose to participate)

Part I: Information Sheet

Introduction
My name is Ashley Clem and I am a Doctor of Nursing Practice (DNP) student at the University of Massachusetts, Amherst. I am doing an integrative review project to gather feedback from caregivers on how to increase awareness of community resources for caregivers who experience elevated levels of stress associated with caregiving. You do not have to decide today whether or not you will participate in the research. You may talk to anyone they feel comfortable talking with about the project plan and can take time to reflect on whether they want to participate in the survey at the completion of the course. If you do not understand some of the words or concepts, I will take time to explain them as we move through the course and questions can be asked at any time.

Purpose of the project
As stated above, I am doing an integrative review project focused on improving caregiver health and decreasing stress associated with caregiving. I will be creating a Caregiver Toolkit for Primary Care to help increase awareness of the Powerful Tools for Caregivers course in the community. My goal is to obtain feedback on the impact of the Powerful Tools for Caregivers course from family caregivers in this course on ways to improve provider identification and referral for services for caregiver distress to improve caregiver health and functioning.

Participant Selection
You are being invited to take part in this research because I feel that your experience as a participant in the Powerful Tools for Caregivers course can contribute valuable information as to why Primary Care providers need to be aware of community resources that focus on caregivers to optimize their health and well-being.

Voluntary Participation
Your participation in this project is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you receive at the Rutland Senior Center in Rutland Massachusetts will continue and nothing will change.

Procedures
A. I am asking you to help us learn more about the importance of caregiver health, diminishing the effects of caregiver stress, and identifying ways to increase awareness among Primary Care providers so that they can assist in identifying caregiver burden and referring caregivers to community resources, such as Elder Services. We are inviting you to take part in this project. If you accept, you will be asked to complete a short survey at the end of the course that will provide feedback to help create a Caregiver Toolkit for Primary Care. This will highlight the importance of a healthy transition into the caregiving role and obtaining tools that are essential throughout the entire caregiving process.

B. You will be asked to fill out a survey, which will be provided and collected by Ashley Clem.

If you do not wish to answer any of the questions included in the survey, you may skip them and move on to the next question. The information recorded is anonymous and your name is not being included on the form.
Duration
The project takes place over the duration of the 6-week course at Rutland Senior Center. Only data will be collected at the completion of the course from the survey as discussed above. Otherwise, I will be conducting the course along with the Master Trainer from Elder Services. I was trained to become a certified Class Leader to become knowledgeable about the Powerful Tools for Caregivers course so that I can educate Primary Care providers on this evidence-based intervention for caregivers in Central Massachusetts.

Risks
If any discussion on sensitive and personal issue arises throughout the duration of the course, it will not be included in the Caregiver Toolkit. If you feel uncomfortable answering a question in the survey after completing the course, you do not have to answer. The Caregiver Toolkit will only be comprised of information pertaining to the Powerful Tools for Caregivers course to educate Primary Care providers on the benefits of the intervention, anonymous feedback from survey, and local community contacts and resources for caregivers (Elder Services of Worcester Area (ESWA), etc.).

Benefits
There will be no direct benefit to you, but your participation is likely to help us find out more about how to prevent and manage caregiver burden in your community.

Reimbursements
You will not be provided any incentive to take part in the project.

Confidentiality
We will not be sharing information about you to anyone outside of the Class Leader and Master Trainer from Elder Services of Worcester Area (ESWA). The information that we collect from this survey after completing the course will be kept anonymous.

Sharing the Results
Nothing that you tell us will be shared with anybody outside the Team Leader or Master Trainer, and nothing will be attributed to you by name. The knowledge that we get from this project will be used anonymously only as generalized feedback as a group for each question in the survey.

Right to Refuse or Withdraw
You do not have to take part in this research if you do not wish to do so.

Who to Contact
If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following: Ashley Clem, 508-574-2266

Part II: Certificate of Consent
I have been invited to participate in a project about improving caregiver health through the use of Powerful Tools for Caregivers course provided by Elder Services of Worcester Area (ESWA). With this project, I understand that the goal is to increase awareness among Primary Care providers and that my feedback, in the form of a survey, will assist in educating providers on the impact of caregiver distress and how it negatively effects their health. With this feedback, I understand that it will help providers to identify distress in caregivers and refer family caregivers to community resources, such as Elder Services of Worcester Area (ESWA) and / or the Project.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant ____________________________
Signature of Participant ____________________________
Date ________________
Day/month/year