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# Mitigating Caregiver Burden

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### Abstract

Informal caregiving is the most common form of long-term care provided in the United States, and with the projected rapid growth of older adults, informal caregiving will be even more critical in the foreseeable future. In the United States, slightly more than 20% of informal caregivers provide care for more than one care recipient, and 10% provide care for three or more care recipients. Caring for a dependent, older adult patient may have negative effects on physical, psychological, psychosocial, social and financial health of caregivers. Careful assessment of the impact of informal caregiving on the caregiver's functioning is imperative, and will enable a practitioner to not only find ways to help caregivers shoulder the effects of caregiving, but also to measure the effectiveness of interventions that seek to mitigate the effects of caregiving.

**Keywords:** caregiver, chronic disease, burden, measuring/alleviating burden

## **Introduction and Background**

The projected rapid growth of older adults in the United States will result in a critical need for informal caregiving in the foreseeable future. An informal caregiver is defined as an unpaid person who provides physical, practical, and emotional care and/or support to a relative or a friend (Candy, Jones, Drake, Leurent, & King, 2011). Caregiver burden is described as the extent to which caregivers perceive that caregiving has an adverse effect on their emotional, social, financial, physical, and/or spiritual functioning (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Perceived caregiver burden predicts anxiety and depression in caregivers, and occurs as a result of perceived inability to contend with role demands (Higginson, Gao, Jackson, Murray, & Harding, 2010). Caregiver burden is viewed as a multidimensional concept affected by both objective and subjective elements (Hatch, DeHart, & Norton, 2014; Higginson, Gao, Jackson, Murray, & Harding, 2010; Van Durme, Macq, Jeanmart, & Gobert, 2012). Objective elements are those related to the nature and time of tasks undertaken, while subjective elements arise from perceived emotions, along with psychosocial stressors. The need exists to measure caregiver burden using psychometrically valid tools so that practitioners can effectively implement and evaluate interventions to reduce caregiver burden.

## **Problem Statement**

The aging population, increased number of people living with chronic disease, and lack of support for informal caregivers, has increased the prevalence of caregiver burden (Adelman et al., 2014). The unmet needs of family caregivers, along with extensive health risk of these caregivers, emphasizes the need for both effective and sustained clinical engagement by practitioners with families to achieve optimal chronic care management outcomes (Gaugler, Potter, & Pruinelli, 2014). Burden among caregivers may be indicated by negative effects on

physical, psychological, psychosocial, social and financial health of the caregiver, and may be primarily caused by unrelieved stressors. Caregiver burden may be mediated by factors such as quality health care, support services and individual resilience. Caregiver burden is dependent on factors such as family, social, and primary care practitioner (PCP) supports that moderate the causes, in addition to prior existence of predisposing factors, such as an existing health care recipient, provider, and vulnerabilities. The problem is that while a patient receives a thorough physical and mental health assessment during a home care visit, the caregiver is not the focus of attention. However, by asking a caregiver to take a simple survey, perhaps a PCP could identify caregiver burden early, before the caregiver develops physical and/or mental health problems, which then impact patient health.

### **Review of the Literature**

A comprehensive search of the literature related to caregiver burden included the following databases: PubMed of the National Library of Medicine, CINAHL, and Ovid SP. The following Medical Subject Headings (MeSH) terms were used for the search: *caregivers*, *chronic disease*, *caregivers and chronic disease*, *caregiver burden*, *measuring caregiver burden* and *alleviating caregiver burden*. Over 5000 articles were retrieved initially from the search. The doctor of nursing practice (DNP) student consulted with an associate university librarian for clinical support services and constructed a more precise PICO question, ‘Caregiver burden: how can family nurse practitioners (FNPs) routinely (easily) monitor (measure), and successfully intervene to ease it?’ Inclusion criteria were also added to include full-text articles in the English language and studies completed within the last five years. The databases were then re-searched using: *caregiver burden*, *chronic illness AND alleviate caregiver burden*. Nineteen studies were

retrieved; excluded were four studies that duplicated each other and six that were descriptive focusing on specific chronic conditions, leaving nine studies for the review of literature.

The studies discussed in this literature review include one systematic review, one randomized control trial (RCT), six systematic reviews of cohort studies, and one descriptive study. The systematic review evaluated interventions for supporting informal caregivers and the RCT used extant data from the Resources for Enhancing Alzheimer's Caregiver Health II study. Of the six systematic reviews, four examined measures of caregiver burden, and two examined caregiver interventions. The descriptive study discussed caregiver burden and meeting complex needs of families. The literature review included studies discussing possible caregiver interventions ranging from pharmacologic measures to anticipatory guidance, along with guidance for future research. After summarizing the literature review, the theoretical framework for the project will be discussed.

### **Caregiver Interventions**

Caregiver interventions that improve outcomes for both patients and caregivers come in a variety of formats from universal, community-based to illness-specific and individualized. Caregiver care can be improved by offering innovations in areas that include self-management, decision support, information systems and delivery redesign (Collins & Swartz, 2011).

**Pharmacologic interventions.** A meta-analysis by Adelman and associates (2014) provided a case study of an 84-year-old female caregiver who attempted suicide (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). The authors found that caregiver burden is a compelling problem that affects caregivers of chronically ill patients, and that there is variation in the threshold at which burden is triggered (Adelman et al., 2014). This is the only article that offered pharmacologic interventions in reducing caregiver burden, specifically for caregivers

who care for patients with dementia (Adelman et al., 2014). Both Van Durme and associates (2012) and Higginson and colleagues (2010) focused on measuring caregiver burden (Higginson et al., 2010; Van Durme et al., 2012). Out of 105 scales measuring caregiver burden, the *Zarit Burden Interview (ZBI)* was identified as easy to use and extensively studied, with the shortened version, the *ZBI-12*, having the best discriminative ability and highest validity of all measurement tools (Adelman et al., 2014; Hatch et al., 2014; Van Durme et al., 2012). Also identified was the need to keep any caregiver burden questionnaire short and to the point, since burdened caregivers are often completely focused on patient needs, not their own experiences, and may not wish to spend time completing anything but the briefest questionnaire (Higginson et al., 2010).

**Stress reduction.** Challenges or common stressors for caregivers include resistant or angry care recipients, long distance caregiving, family disagreements, physical care needs, change, uncertainty, poor/ineffective medical care, money, legal matters, and difficult caregiver feelings such as frustration, anger, guilt and depression. The first stages of caregiving have been shown to be the most demanding since this is when caregivers not only are the least informed of what is needed and expected, they are also unaware of potential resources, which leads to insecurity and uncertainty (Family Caregiver Alliance [FCA], 2010). Research has indicated that caregivers who are supported are more likely to provide quality, safe care to loved ones, resulting in improved quality of life for both (Carter, 2012). Three levels of intervention could be offered: (1) universal – providing all caregivers with basic information and skills to assist them in their role (2) selective – caregivers with minimal risk on assessment are provided with skills training and group support programs, and (3) indicated – caregivers with high levels of risk are provided with tailored, multi-component, intensive support programs (Carter, 2012). These three



levels of intervention are comparable to the common typology found in public health, namely primary, secondary and tertiary prevention measures (Issel, 2014). Interventions that can be offered may be found in Appendix B, Table 1.

Three research studies were conducted to investigate the best way to care for caregivers. Themes that emerged included helping caregivers live normal lives by lowering distress levels, understanding when and how caregiving began to help families identify potentially helpful interventions earlier, and focusing on caregivers with high subjective stressors (Gaugler et al., 2014; Hatch et al., 2014; Simonic, Furlan, Ravnjak, & Dirkse, 2012).

Van Houtven et al. (2011) presented an organizing framework for caregiver interventions. The concepts within this framework include assessment of caregiver activities such as clinical knowledge, coping skills and support systems, as well as determining the relationship between caregiver interventions and outcomes on psychological and physical health of both the caregiver and care recipient. A systematic review conducted by del-Pino-Casado et al. (2011) identified that caregiving interventions should be based on coping skills such as problem solving and positive reappraisal (del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Pancorbo-Hidalgo, 2011; Van Houtven et al., 2011).

**Support interventions.** Support groups or psychoeducational interventions for caregivers were found to be modestly effective in relieving caregiver burden (Adelman et al., 2014; Gaugler et al., 2014). Practical supports, such as domestic or respite care and food delivery services, may also provide enough relief for a caregiver to engage in health-promoting behaviors that include exercise or other activities that may improve quality of life (Adelman et al., 2014; Candy, Jones, Drake, Leurent, & King, 2011; Simonic et al., 2012; Van Durme et al., 2012).

Caregiver coping may be improved with counseling about caregiver stress, its consequences, and strategies to ameliorate stressors. These coping mechanisms may include developing problem solving skills, learning how to ask for help, engaging other family members in care, participating in support groups, and ensuring preservation of caregiver health (Adelman et al., 2014; Candy et al., 2011; del-Pino-Casado et al., 2011; Hatch et al., 2014; Simonic et al., 2012).

Technology may be used to facilitate independent functioning for the care recipients and reduce their dependency on the caregiver. These supports include items such as emergency response systems, home intercom systems, mobility monitors, lift systems, and online support groups (Adelman et al., 2014; Simonic et al., 2012).

Caregivers may not even be aware of assistance available to them or know if they qualify for help. Partnership-based practice between families and practitioners offers an ideal platform from which to deliver or refer families to appropriate caregiving services such as home health care, medical adult day programs, and transportation and meal delivery services (Adelman et al., 2014; Gaugler et al., 2014).

And, most importantly, attention to symptom relief for care recipients with chronic medical conditions may not only improve their quality of life, but may also help to alleviate caregiver distress (Adelman et al., 2014; Simonic et al., 2012). The Cochrane review (Candy et al., 2011) found that interventions directly supporting caregivers not only helped the caregivers cope with their emotions and roles, but, they also improved the caregiver's quality of life.

However, due to limited trial data, variability in types of interventions and evaluation methodologies, the authors were not able to specify which intervention provided the greatest potential benefit, was most acceptable, how it was best delivered, and which caregivers

benefitted most (Candy et al., 2011). Van Houtven and associates (2011) stipulate that caregiver interventions must seek to change the activities of caregiving, which then affects both caregiver and care recipient outcomes. Recommendations to guide interventions made by the authors include assessing both the quality and quantity of caregiving activities and, in addition, assessing how well the interventions work (Van Houtven et al., 2011).

**Anticipatory guidance.** Evidence suggests that when both patient and caregiver are treated as a dyad, outcomes for both improve (Collins & Swartz, 2011). The placement of care recipients into a long-term care facility, or care recipient death, results in increased caregiver anxiety; to ease these transitions, PCPs should provide anticipatory guidance, assistance with advance care planning and resources for long term and end of life care (Appendix B, Table 2).

Funding for caregiver services in limited amounts is available through

- The Family Medical Leave Act
- The Department of Veterans Affairs Programs
- The Centers for Medicare and Medicaid Services' Home and Community-based Care Programs
- Program of All-Inclusive Care for the Elderly
- Respite Care
- Selected Adult Day Care Services
- Cash and Counseling Programs in which Medicaid beneficiaries with a disability can receive cash vouchers to pay family members who provide caregiving.

However, despite these programs, caregiver funding is insufficient and varies from state to state (Collins & Swartz, 2011). Barriers between PCPs and caregivers that may arise include: ethnic or cultural issues, filial obligation (willingness to give/accept care), fear of strangers being

in the home, embarrassment, and “we’re not like that” (FCA, 2010) – never having had to ask for help or access medical systems. PCPs can facilitate the caregiving process by understanding the complexities caregivers are facing, helping them to self-identify as caregivers, listening to their concerns, acknowledging their feelings and encouraging them to seek assistance (FCA, 2010).

### **Future research**

Future research on caregiver burden needs to focus on identifying components of perceived burden (Higginson et al., 2010) along with a widely accepted definition of an informal caregiver (Adelman et al., 2014; Candy et al., 2011; Gaugler et al., 2014; Van Durme et al., 2012). Areas that should be a focus of further research include caregiver interventions assessing both quantity and quality of provided care, and interventions considering a common set and broader range of caregiver/care recipient outcomes (Van Houtven et al., 2011). Limitations in the literature reviewed include a lack of RCTs testing the efficacy of clinical approaches to relieving caregiver burden (Gaugler et al., 2014), fairly select samples which are not generalizable (Adelman et al., 2014; Candy et al., 2011; del-Pino-Casado et al., 2011; Gaugler et al., 2014; Higginson et al., 2010; Simonic et al., 2012; Van Houtven et al., 2011) and use of secondary analyses which may result in missed key evaluations of studies or in transcription error (Van Durme et al., 2012; Van Houtven et al., 2011). In sum, the research conducted to date has several methodological limitations leaving several opportunities to improve the state of the science related to reducing caregiver burden.

### **Summary**

The aging population, increased number of people living with chronic disease, and the lack of support for informal caregivers, has increased the prevalence of caregiver burden (Adelman et al., 2014). The unmet needs of family caregivers, along with extensive health risk,

emphasize the need for both effective and sustained clinical engagement with families to achieve optimal chronic care management outcomes (Gaugler et al., 2014). Risk factors for caregiver burden that should trigger assessment include around the clock care, high or increasing care needs and care transitions (Adelman et al., 2014). Effective interventions include providing respite care (Adelman et al., 2014; Candy et al., 2011; Gaugler et al., 2014; Simonic et al., 2012; Van Durme et al., 2012), improving coping skills (Candy et al., 2011; Gaugler et al., 2014; Simonic et al., 2012), improving well-being with psychological programs such as counseling or psychotherapy (Candy et al., 2011; Gaugler et al., 2014; Simonic et al., 2012), symptom management for patients (Adelman et al., 2014; Simonic et al., 2012), effective communication along with community-based supports (Gaugler et al., 2014), and providing interventions at the appropriate time (Candy et al., 2011; Simonic et al., 2012). Due to the increasing prevalence of caregiver burden, public awareness campaigns have been launched for community members to become aware of the fact that they are caregivers and that help is available; one of these public awareness campaign sites is found at <http://www.whatisacaregiver.org/caregiving-for-others.html> (Gaugler et al., 2014). Addressing caregivers' needs is not a straightforward task; their needs are broad ranging and change over the period of caregiving (Candy et al., 2011).

Multiple interventions were included in this project to facilitate alleviation of caregiver burden; each intervention addressed one of the several factors involved in caregiver burden. These interventions are grouped in Appendix B, Table 3. The literature review demonstrated that it was important to use interventions that had not only been shown to be effective, but that were also tailored to the characteristics of the target population (Issel, 2014). Interventions must be adjusted to the specific needs of the caregivers, and must result in health gains. Program interventions need to be tailored to reach a specific target audience, match the level at which the

intervention is aimed to the level where the target audience exists, and also match the level at which the outcome is desired (Issel, 2014).

### **Organizational and Theoretical Frameworks**

This quality improvement project used a theoretical framework, stress process theory, and an organizational framework, which detailed both the components of the caregiving activities as well as the caregiver and care recipient outcomes that should be affected by intervention. This organizational framework allowed the practitioner to assess the quality and quantity of, and change within, caregiving activities. It also allowed the practitioner to evaluate the efficacy of interventions, to assess patient and caregiver outcomes, and to facilitate future cross-study comparisons of effectiveness (Van Houtven et al., 2011). This project included multiple interventions, each addressing one of several causes of caregiver burden. The interventions listed are evidence based, tailored to the characteristics of the target population, result in health gains, can be manipulated, and were logistically doable within the context of the project (Issel, 2014). The fundamental principles for caregiver assessment and intervention include:

- (1) Family caregivers are a core part of health care, thus, it is important to recognize, respect, assess and address their needs.
- (2) Caregiver assessment is completed from a family-centered perspective, including the needs/preferences of both care recipient and provider.
- (3) Caregiver assessment results in a collaborative care plan with measureable outcomes.
- (4) Caregiver assessment encompasses a multidimensional approach and must be periodically updated.
- (5) Caregiver assessment reflects culturally competent practice (FCA, 2006).

Stress process theory was first described by Pearlin (1989) as a combination of three major conceptual domains: exposure to sources of stress, strategies for coping, and outcomes related to stress. In 1995, Aneshensel and associates further noted that “the conceptual framework of the stress process is particularly useful in capturing the dynamic features of problematic life experience, caregiving being an excellent case in point” (p. 35). Common sources of stress associated with caregiving include: changes in role function, additional financial responsibilities, assisting with activities of daily living and dealing with potential behavioral problems of care recipients (Sundar, 2014). Caregiving may create a context in which caregivers experience stress and burden, but methods of coping among caregivers vary considerably. Outcomes associated with caregiving are dependent on many factors including available resources, caregiver characteristics and individual perception of burden. “The meaning a caregiver gives to events; that is, the amount of perceived threat and how disruptive the event is to their lives, impacts how they respond to those events and, ultimately, to the outcomes they experience” (Sundar, 2014, p. 751). Pearlin (2010) has added to his own work, seeing the problem of caregiving increasing as the population ages, noting that becoming a caregiver is not a normal expected life transition, and so one is not prepared for it; some have labeled it the unexpected career (Aneshensel et al., 1995). The caregiver role can become totally engulfing, displacing one’s other roles, reshaping one’s life course and it may adversely affect both health and well-being.

Interventions to support caregivers must use a person-centered approach, because services offered must be driven by the needs and desires of the patient and the caregiver. To be successful, interventions must support informed decision making, creative problem solving and negotiating individually designed agreements for care (Sundar, 2014). Van Houtven and

associates (2011) offer an organizing framework that was utilized in planning caregiver interventions (Appendix A). This organizing framework stipulates that any interventions should seek to change caregiving activities, which then in turn affect caregiver and recipient outcomes (Van Houtven, 2011). It is apparent from this organizing framework that caregiver and care recipient outcomes affect each other, and both feedback about caregiving activities, and a successful program will set into motion the interventions, or causal processes, that lead to the desired outcome (Issel, 2014). In any model or theoretical framework, PCPs work alongside patients to engage in health-promoting processes and achieve client goals. This initial project focused on baseline characteristics, activities and interventions associated with caregiving; it could be expanded in the future to include measurement of outcomes.

### **Project Design and Methods**

#### **Setting and Resources**

The capstone project took place in a home visit practice that utilizes both physicians and nurse practitioners. PCPs “can aid in the identification, support, and treatment of caregivers by offering caregiver assessment – interviews directed at identifying high levels of burden – as soon as caregivers are identified” (Collins & Swartz, 2011, p. 1309). The PCP, while preserving patient autonomy and privacy, also needs to validate the caregiver role and help resolve potential conflicts between the needs and rights of both the care recipient and the caregiver (Collins & Swartz, 2011).

**Description of the group, population, community.** The specific target dyads of this project consisted of homebound patients and their caregivers who were eighteen years of age or older. PCPs saw patients of all ethnicity, race and socioeconomic status; these demographics were dependent upon the specific areas within the county where visits were scheduled.



**Organizational analysis of project site.** This home visit practice is a PCP house call practice, which strives to reach seniors and homebound patients with a more convenient method of providing high quality medical care. The PCPs visit patients in their homes, assisted-living facilities, skilled nursing facilities, retirement homes or retirement communities. Providers currently visit patients throughout Burlington, Camden and Gloucester Counties in New Jersey. The convenient, coordinated, preventative care provided greatly reduces the risk of declining health conditions and significantly decreases the likelihood of an emergency room visit or a hospital stay. The home care provided consists of complete medical and diagnostic services using the latest technology to achieve the same level of care that would be found in a primary care office. Some of the most common medical conditions providers manage include Alzheimer's and related dementia, stroke, pain management, palliative care, cardiac, pulmonary, and/or renal disease, diabetes, hypertension, wound care and general debility.

The comprehensive services of this home visit practice allow patients to be assessed thoroughly and appropriately treated by a highly trained PCP in the comfort of home without the worry of long stays in waiting rooms, high transportation costs or caregivers missing work to make the appointments. This practice provides a wide array of comprehensive medical treatments and services including complete history and physical evaluations, hospice and palliative care evaluation, medication orders and adjustments, arrangement of specialist consultations, 24 hour access to a PCP, and communication with visiting nurse organizations regarding treatment plans. PCPs will coordinate home medical treatments such as laboratory studies, x-rays, nutritional assessments, venous and arterial ultrasounds, dietary counseling, speech, occupational and physical therapies and elder health legal services.

The founder of this practice is a board certified internist. A board certified physician performs every initial home visit. The full staff of home visit providers also includes certified family and geriatric nurse practitioners who see the patients on subsequent follow-up visits.

The DNP student interacted with office staff while picking up patient medical records in the morning, and discussing any necessary information for the day; then the day was spent conducting home care visits and documenting findings. The home visit schedule is completed by office staff who review each chart after a home visit, and schedule the next visit based on patient need – usually between four to six weeks. Each practitioner picks up a detailed list with patient names, addresses, and visit confirmation details in the morning; this list may be altered at the last minute if a patient phones in with the need for an immediate sick visit. These home visits allowed interaction with caregivers for project implementation. The DNP student completed a needs assessment using the adapted *Zarit Screen Measure of Caregiver Burden Interview [ZBI-12]* (Collins & Swartz, 2011) on any caregiver of patients visited who were willing to complete the survey. The goal was to focus on the “strength, assets, abilities, and resources that exist and are available” (Issel, 2014, p. 124) and work toward a practice change that would help identify caregiver burden and provide health care providers with resources to help patients. Any follow-up required on lab work, x-rays, prescriptions, etc. was received via phone call from office staff, and return calls were made by the NP while en route. Charts were returned to the office when completed, and filed by office personnel. This office time allowed the DNP student to share the survey instrument and interventions as a toolkit with other providers.

**Evidence of stakeholder support.** Stakeholders in this project include the staff of the home visit practice: two physicians, three FNPs, a scheduler, a biller, and a receptionist. Stakeholders provided support to the project because by being invested in the findings, they were

more likely to believe the findings. Involvement of all of the stakeholders in this practice resulted in improved outcome assessments; expectations were acknowledged, discussed and determined to be realistic as to project outcome.

**Facilitators and barriers.** Facilitators to project implementation included stakeholder support and the structure of home care visits allowing access to caregiver interviews. The DNP student received strong support from preceptors, which has allowed access to other providers at the practice, which enhanced the ability to share the survey tools and interventions. The DNP student has also received strong informal support at the university level to include access to available resources.

Barriers identified in the practice setting included: no existing tool used to evaluate caregiver burden, lack of interaction with the caregiver about his/her own health, and an absence of specific interventions proven to alleviate caregiver burden. Strategies to overcome these barriers included: use of the *ZBI-12* to evaluate caregiver burden at each home visit (Van Durme, Macq, Jeanmart, & Gobert, 2012), developing a relationship not only with the patient, but also with the caregiver (Gaugler, Potter, & Pruinelli, 2014), and sharing the effectiveness of interventions utilized to mitigate caregiver burden with other providers (Van Durme et al., 2012). Barriers to implementation of these measures included the length of time allotted to each patient visit (about 30 minutes/patient), the caregiver not being home or refusing to fill out the caregiver assessment tool, follow-up with the patient and caregiver was assigned to another care provider, and lack of practitioner knowledge concerning available resources.

### **Goals, Objectives, and Expected Outcomes**

Goal: Caregiver burden was measured using the *ZBI-12*.

<b>Objective:</b>	<b>Expected outcome:</b>
To assess caregiver burden on all adult	Caregiver burden will be measured at the

caregivers (>18 years of age) encountered on home visits willing to complete the <i>ZBI-12</i> .	initial visit using the <i>ZBI-12</i> . 90% of caregivers expected to comply with measurement request.
To repeat assessment using the <i>ZBI-12</i> with change in status of either the caregiver or care recipient.	Caregiver burden will be re-measured on the <i>ZBI-12</i> at subsequent home visits (as allowed given PCP's schedule); expect to revisit 20-30% of patients/caregivers.
To validate the caregiver role and help resolve potential conflicts between needs/rights of both care recipient and caregiver.	Identification of challenges and/or common stressors during the initial visit to include: resistant or angry care recipients, long distance caregiving, family disagreements, physical care needs, uncertainty, poor/ineffective medical care, money, legal matters, frustration, anger, guilt and depression; informal evaluation of 100% of caregivers.

Goal: Caregivers and patients expressed improved understanding of the applicable disease process.

<b>Objective:</b>	<b>Expected outcome:</b>
To identify lack of knowledge, since the first stages of caregiving have been shown to be the most demanding; this is when caregivers are least informed of what is needed and expected.	Patient and caregiver referred to disease specific advocacy organization for most up to date resources and information during initial visit; expected presentation to 100% of caregivers.
To provide support to caregivers.	Ongoing provision of quality, safe care to loved ones, resulting in improvement in quality of life for both; informal support to 100% of caregivers.
To identify end-goals for care.	Provision of decision-making tools at initial visit; assistance provided for end of life planning as applicable; expected presentation to 30-40% of caregivers.

Goal: Caregivers with high scores on the *ZBI-12* experienced a reduction in burden.

<b>Objective:</b>	<b>Expected outcome:</b>
Determine the level of intervention needed as universal, selective or indicated.	Appropriate interventions are offered at the initial visit, which may include (100%) <ul style="list-style-type: none"> <li>• The caregiver's pledge</li> <li>• Help to set limits</li> <li>• Information about support groups</li> <li>• Referrals to PT, OT, ST, and hospice</li> <li>• Links to caregiver resources</li> <li>• Referral for psychoeducation and/or</li> </ul>

	therapy through home behavioral health
To provide applicable handout information.	Handouts printed and ready include (100%) <ul style="list-style-type: none"> <li>• The ZBI-12</li> <li>• The Caregiver’s Pledge</li> <li>• My Medicine List</li> <li>• The Conversation Starter Kit</li> </ul>
To provide caregiver interventions.	Interventions will impact caregiver activities with improvement in both caregiver and care recipient outcomes, which may be observed at subsequent visits (20-30%).
To share survey tool and interventions as a toolkit with other providers at the home visit practice.	Toolkit will be shared with 100% of FNP providers; 90% of FNP providers will give feedback on interventions.

### Implementation

The DNP student, along with the FNP preceptor, completed 112 clinical hours consisting of home visits as PCPs. Each eight hour shift began with first going to the home visit practice to pick up the schedule and patient charts. At each home visit, if there was a caregiver present, they were invited to complete the *ZBI-12 Survey*. The *ZBI-12 Survey* includes the following questions:

1) Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
3) Do you feel angry when you are around the relative?
4) Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?
5) Do you feel strained when you are around your relative?
6) Do you feel that your health has suffered because of your involvement with your relative?
7) Do you feel that you don’t have as much privacy as you would like because of your relative?
8) Do you feel that your social life has suffered because you are caring for your relative?

9) Do you feel that you have lost control of your life since your relative's illness?
10) Do you feel uncertain about what to do about your relative?
11) Do you feel you should be doing more for your relative?
12) Do you feel you could do a better job in caring for your relative?

Responses to these questions include never (0), rarely (1), sometimes (2), quite frequently (3), nearly always (4). During project implementation, 51 patients were seen, and nine surveys were completed by caregivers. The survey score was calculated during the patient visit to determine the *Implementation Plan of Action* needed: Universal (0-19), Selective (20-35), and Indicated (36-48); once the plan of action was determined, the selections within these categories were reviewed (Appendix B, Table 3). For instance, a score of two fell within the universal *Plan of Action*. The caregiver in this household could be offered the caregiver pledge, information about the patient's disease process, information about support groups, and offered the medication tracking tool. Once it was determined if the caregiver wished further information, the DNP student consulted *Possible Interventions* (Appendix B, Table 1), and shared the available interventions with the caregiver. After consulting with the caregiver and desired interventions were determined, the DNP student consulted *Possible Resources* (Appendix B, Table 2). For instance, the caregiver could be given general caregiver information or disease specific advocacy organization information, in addition to a medication tracking tool. The DNP student consulted the *Caregiver Burden Intervention Flowchart* (Appendix 1, Figure 1) to assess the caregiver activities of clinical knowledge, psychological self-efficacy and coping, support seeking and quantity of caregiving to assess if further intervention was needed and/or desired by the caregiver. This flowchart would be extremely useful on return visits, to see if the intervention was reflected in both caregiver and care recipient outcomes.

Information concerning the DNP student's findings on caregiver burden, along with the interventions from the literature, was disseminated to the FNPs at the home visit practice and a

copy of this information was left in a binder for future reference. A survey was constructed to elicit feedback from the FNPs in the practice on the usefulness of this information; no surveys have been returned to date.

Facilitators to project implementation included the support of the home visit practice in allowing the DNP student to complete the project in the practice, along with the support of the FNP preceptor. In addition, most of the caregivers who were home were willing to complete the *ZBI-12* survey if they were able.

### **Cost-Benefit Analysis/Budget**

The financial budget for the project was low, with total cost of \$20.00/month, and a \$50.00 gift card for the FNP preceptor at the end of the project as outlined in Table 4.

Table 4

#### *Cost Itemization*

<b>Item</b>	<b>Cost</b>
<b><i>Physical Materials</i></b>	
Permission for use of <i>ZBI-12</i> , The Conversation Starter Kit, The Caregiver's Pledge, and My Medicine List	\$0 (no applicable charges from agencies for permission and use of these forms)
Copies of documents above (75 of each – 300 total)	\$0 (in-kind donation) – estimated value \$177.00
2 reams of printer paper	\$0 (in-kind donation) – estimated value \$12.98
1-3 pack of black ballpoint pens	\$0 (in-kind donation) – estimated value \$8.99
<b><i>Computer Information Systems</i></b>	
Roaming wireless for home visits to record information for capstone project	\$20/month x4months = \$80.00
<b><i>Personnel</i></b>	
Preceptor for home visits	\$50.00 gift card (DNP student)
<b><i>Project space for Program Implementation</i></b>	
The home visit practice office space/ Patient homes	\$0 (no charge for use of office space)
<b><i>Total Cost/Expenses</i></b>	
Total estimated cost	\$328.97

Total estimated cost for project (minus costs of donated services)	- 198.97
<b>Total Actual Cost</b>	<b>\$130.00</b>

Actual cost funded by the DNP student included the roaming wireless monthly cost and a gift card for the FNP with the home visit practice. The DNP student received free permissions for the tool to be used, along with patient handouts. The cost of office supplies and printing was absorbed by the DNP's place of employment.

There was no loss of revenue since the DNP student accompanied the FNP on scheduled home visits. Revenue generated by patient home visits remained unaffected; both patients and providers benefitted from careful assessment of the impact of caregiving on the caregiver's function, and attempting to find ways to help caregivers shoulder the effects of caregiving. Therefore, the benefits of this project largely outweighed any potential costs, or overhead donated by involved parties.

### **Ethics and Human Subjects Protection**

This project involved the use of surveys given to the caregivers of patients seen on home visits. The caregiver, rather than the patient, was the human subject. Given the program evaluation design of the project, as well as lack of risk posed to participants, it was exempt from IRB requirements.

There was no identifiable or discernible risk to participants, nor was there a need to identify any participants' identity (i.e., the study collected only *ZBI-12* surveys, and initiated a plan to alleviate burden if detected). Confidentiality was maintained at all stages because surveys were not identified with names. The protection of data collected was maintained in a locked cabinet in the DNP student's home. The DNP student did not use the practice-associated electronic medical record for the study, and no patient data was entered in the laptop, therefore,



there was no breach in policies surrounding the Health Insurance Portability and Accountability Act.

### Results

According to Pearlin (1989) the stress process is a combination of exposure to sources of stress, strategies for coping, and outcomes related to stress. Van Houtven and colleagues (2011) felt that caregiver intervention was central to improving both caregiver and care recipient outcomes by providing clinical knowledge, improving self-efficacy and coping, providing supports and assessing the quantity and quality of the caregiving provided.

The scores obtained from the nine *ZBI* surveys obtained were as follows:

Score	Number of Respondents
0	2
2	2
5	1
9	1
11	1
18	1
20	1

The DNP student analyzed the results of the *ZBI-12* surveys as to level of intervention needed to include (a) universal – providing all caregivers with basic information and skills to assist them in their role (lowest score = 0) (b) selective – caregivers with minimal risk on assessment would be provided with skills training and group support programs (median score = 24), and, (c) indicated – caregivers with high levels of risk would be provided with tailored, multi-component, intensive support programs ([highest score = 48][Carter, 2012]). The scores from eight of the surveys fell within the universal plan of action. These caregivers were all given the *Caregiver's Pledge* (Appendix B, Table 1) encouraging them to take a break, take care of their own health, maintain a healthy diet, exercise, and seek their own preventive health care. The DNP student also asked if they had help, or belonged to a support group, and if they were

able to manage patient care with the supports in place in the home. The DNP student noted that these caregivers with low levels of stress, identified by their low scores on the *ZBI-12* survey, had caregiving as their sole responsibility. These caregivers did not work outside the home, or have other familial responsibilities or financial worries. One caregiver scored a 20 on the *ZBI-12* survey, indicating a *Plan of Action* in the selective category (Appendix B, Table 3). This caregiver had taken care of her husband, who passed away a few months ago, and was also taking care of her mother at the same time. In consulting Appendix B, Table 3, options included identifying patient needs and symptoms to manage pain control, practical supports, enlisting family and/or church groups for support, technology/home modification tools, referrals, end of life planning and long term placement. Applying the *Intervention Flowchart* (Appendix A, Figure 1), the DNP student assessed this caregiver's clinical knowledge of the patient's condition, self-efficacy and coping, and available supports. Although teary, the caregiver was able to speak about her husband and his death, and her mother was seated in the living room with us, contributing to the conversation. The caregiver's adult son had recently moved in with them, and was helping with groceries and care of the home, and in addition, the caregiver had joined a bereavement support group. She did accept a medication tracking tool (Appendix B, Table 2), although she declined help in filling it out.

The expected outcome was that 90% of caregivers would comply with measurement request; this outcome was not met, since 42 out of 51 did not complete the *ZBI-12* survey, the completion rate was 18%. The DNP student was not able to repeat assessment at three subsequent home visits since the caregivers declined; expected outcome for repeat assessment was 20-30%, and was not met at 0%.

### Discussion

The literature search revealed the fact that people are living longer, and informal caregiving will be ever more critical in the near future. The number of unpaid hours of caregiving provided weekly in the U.S. equals 1.2 billion dollars (Shaw, 2015). He (Shaw, 2015) also found that the proportion of caregiving provided to people 80 years and older by people of the same age was 20%, and that the number of daily hours of caregiving typically received by elderly people was only one and a half. During the course of the project, the DNP student saw two married couples, all patients, where one spouse cared for the other – neither in exceptionally good health. One husband with advanced Parkinson's disease fell almost daily while caring for his wife with dementia. Another wife with beginning dementia cared for a husband with severe cardiac disease. Neither couple had children, although all had some in-home care for part of the day. Sixteen patients had no caregiver; this meant these patients were alone after their aide completed their care for the day.

According to the *Fitzgerald Health Education Associates*, FNPs encounter caregivers every day in practice. These encounters provide the opportunity to practice preventive care - investigating what caregivers need to take care of themselves. Once caregivers are identified, and support and services provided, they are better able to manage the challenges faced every day, hopefully avoiding the negative effects that caregiving can have on health and well-being. This person-centered approach can only be successful if the approach used supports informed decision making, creative problem solving, and strategies that engage support and negotiate agreements that meet the individual and unique needs of each patient and caregiver encountered, as identified by survey results.

Sundar (2014) noted that caregiving is a very individualized process. The meaning caregivers give to events, such as perceived threat or disruption to their lives, impacts their response and the outcomes of caregiving. The DNP student found that for many married couples, although it displaced the roles they were accustomed to, and reshaped their life course; it did not adversely affect their health or their well-being. For grown children, still working full-time, it was an unexpected career (Aneshensel et al., 1995); some coped well, others did not.

The DNP student found the results of the project unexpected; the intention was to survey a caregiver at each home, and to have repeat assessment results. This outcome, 9 surveys/51 patients, was particularly disappointing since reassessment of burden and outcomes using the *Intervention Flowchart* (Appendix A, Figure 1) was not possible. The outcome for determining the level of intervention needed offered at initial visits was 100%; interventions were determined by the *Implementation Plan of Action* (Appendix B, Table 3).

Several reasons prevented the completion of the surveys by 42 caregivers:

Husband and wife were both patients, and one spouse was the caregiver of the other	2
No caregiver was present	12
The caregiver refused	4
The caregiver had intellectual developmental disorder	3
The patient had no caregiver	16
Survey was left at the request of the caregiver, but not completed	2
Return visit where the survey was already completed.	3

The DNP student noted, particularly with caregivers that refused the survey, a high level of stress. These caregivers rushed home from work, or rushed around getting ready to leave, with little time to devote to answer questions about their own needs. Of particular interest was the number of patients with no caregiver readily available, or even local to the patient. These results illustrate that caregiving can and does result in stress. However, the DNP student was limited in

identifying only low levels of stress in those surveyed, and unable to measure how well interventions worked or assess outcomes related to those interventions.

The biggest barrier to implementation was the fact that a majority of caregivers were not home during the day. The second barrier was that some caregivers came home specifically for the FNP visit, or were in a hurry to leave for work or other activities, and did not want to take the time to complete a survey. Another barrier to data collection was that a majority of the home bound patient population had no caregiver in the immediate vicinity, sometimes even out of state; these patients may have a home health aide present, or one coming for a few hours during the day. The greatest limitation was that caregivers who were home all day, with caregiving as their sole obligation, did not score high values on the *ZBI-12* survey. Caregivers who were at work and/or out of state would most likely score high on the *ZBI-12* survey; however, these caregivers were not accessible to take the survey. According to Wynn (2016), day to day caregiving is demanding, but caring from a distance has its own set of emotions and complexities – now guilt about not being there is involved. Long distance caregivers find it difficult to move family members away from the home and communities they love, and so employ options such as geriatric care managers, video calls and utilization of the Family and Medical Leave Act. Eight expert-approved strategies to bridge the gap of long distance care are offered by Wynn (2016, p. 23).

These results correspond with the literature, in that burdened caregivers are completely focused on patient needs, not their own experiences, and may not wish to spend time completing even a brief questionnaire. The organizing framework for this project stipulated that any intervention should seek to change caregiving activities, which then in turn would affect both caregiver and recipient outcomes. However, the DNP student found that sometimes just the PCP

visit was intervention enough; both the caregiver and the patient anticipated the visits, and required no other intervention; this is important information for home visit practitioners to recognize.

The negative aspects of caregiving have been identified by the DNP student. However, at these homes where visits are anticipated, what is the difference? Why do some caregivers as well as PCPs note positive aspects of caregiving? Positive aspects of caregiving can be experienced in a variety of areas (Strouth, 2016). These aspects include: (1) strengthening the relationship between the caregiver and care recipient; a feeling of giving back to the person what they have received (2) personal fulfillment with mastery of new skills and a sense of purpose or meaningfulness, and (3) a desire to prevent negative outcomes for the patient. This article (Strouth, 2016) delineates an exercise for caregivers to participate in, to help them understand their caregiving story and give it meaning. This positive view of caregiving may make the *ZBI-12* survey, as it exists, difficult for caregivers to identify with and respond to. Positive aspects of caregiving could and should be incorporated into the *ZBI-12* survey, to allow caregivers to express both positive and negative feelings. Alternatively, The *Patient Health Questionnaire-2* (Kroenke, Spitzer & Williams, 2003) could be used as a quick depression screen for caregivers rather than a written survey. This survey asks over the past two weeks, how often have you been bothered by (1) little interest or pleasure in doing things? (2) feeling down, depressed or hopeless? (0-3 scale)

Study limitations included time constraints, namely a three month clinical rotation with a home visit population, and the use of an in-person survey method leading to an inability to reach a majority of caregivers. Further study could incorporate phone calls, or mailed or online surveys. The DNP student recommends a longer project to incorporate initial *ZBI-12* survey

scores, interventions as provided with this project, and then remeasurement of the *ZBI-12* survey. Perhaps, using the Strouth (2016) article, more positive questions could be incorporated to balance the questionnaire. The positive aspects of caregiving could be identified by questions such as: What is something important that you can identify about being a caregiver? What does caregiving mean to you? What feelings go along with these words? What are some different ways you care? Using the *Intervention Flowchart*, caregiver activities could be measured to include: Did clinical knowledge improve? Is the caregiver coping? Did the caregiver seek out the support services recommended? Did the quantity/quality of caregiving increase/decrease?

The DNP student was also unable to determine if the caregiver population not surveyed would have been the population with high burden scores. This population could be the most impacted by intervention, if able to be contacted by phone or e-mailed survey. The DNP student was aware of a caregiver, who was seen by a PCP on a Friday and denied any problems, and committed suicide over the weekend – this was the inspiration for this translation project; this is the caregiver population that needs to be reached.

Future projects on caregiver burden should be targeted at reaching the caregivers who work outside the home, or live in another state, with telephone calls, mailed surveys or obtaining e-mail addresses and posting the *ZBI-12* online, using a tool such as *SurveyMonkey*. This population is important to reach, along with those who declined surveys, since they may be the population most at risk for high caregiver burden. Future projects could also be targeted at looking at caregiver burden as it relates to diagnosis, hospitalization and hospice of chronic home care patients, and the effects of these conditions on caregivers.

### **Conclusion**

The goals of this project were to measure caregiver burden in a home bound adult population, to identify high caregiver burden, and institute measures to mitigate the caregiver burden. The *ZBI-12* survey was used as the tool to measure caregiver burden, however, a majority of caregivers either had low scores, indicating very low caregiver burden stress, or refused to complete the survey. There is much literature revealing the existence and impact of caregiver burden, and many interventions offered in the literature. The DNP student developed an extensive list of interventions, however, was not able to employ many of them during the course of this project due to low caregiver burden scores. No caregivers opted to complete the survey on return visits, and so the organizational framework could not be utilized to determine if outcomes had been affected.

This project did reveal that caregivers, who have the sole responsibility of caregiving, do not score highly on the burden scale. This project also revealed that a method of reaching caregivers who may have high burden scores must be determined. The home visit practice could start its own caregiver support group, and members could initiate a blog site to share both feelings and caregiving tips; focus groups could be added as needed to deal with health-related topics. The DNP student could apply for funding to offer computer tablets for home-bound patients and caregivers, as well as offer gift cards for completing surveys. By reaching out to caregivers and building stronger relationships we can support both physical and mental health by building on strengths, facilitating resilience and bolstering areas that need informational, instrumental, emotional or relational support.

Only if these highly burdened caregivers can be reached, and interventions implemented, could intervention outcomes be measured. PCPs are in an optimal position for assessment of



homebound patients, but a method for assessment of caregivers and identification of needed supports is still to be determined.

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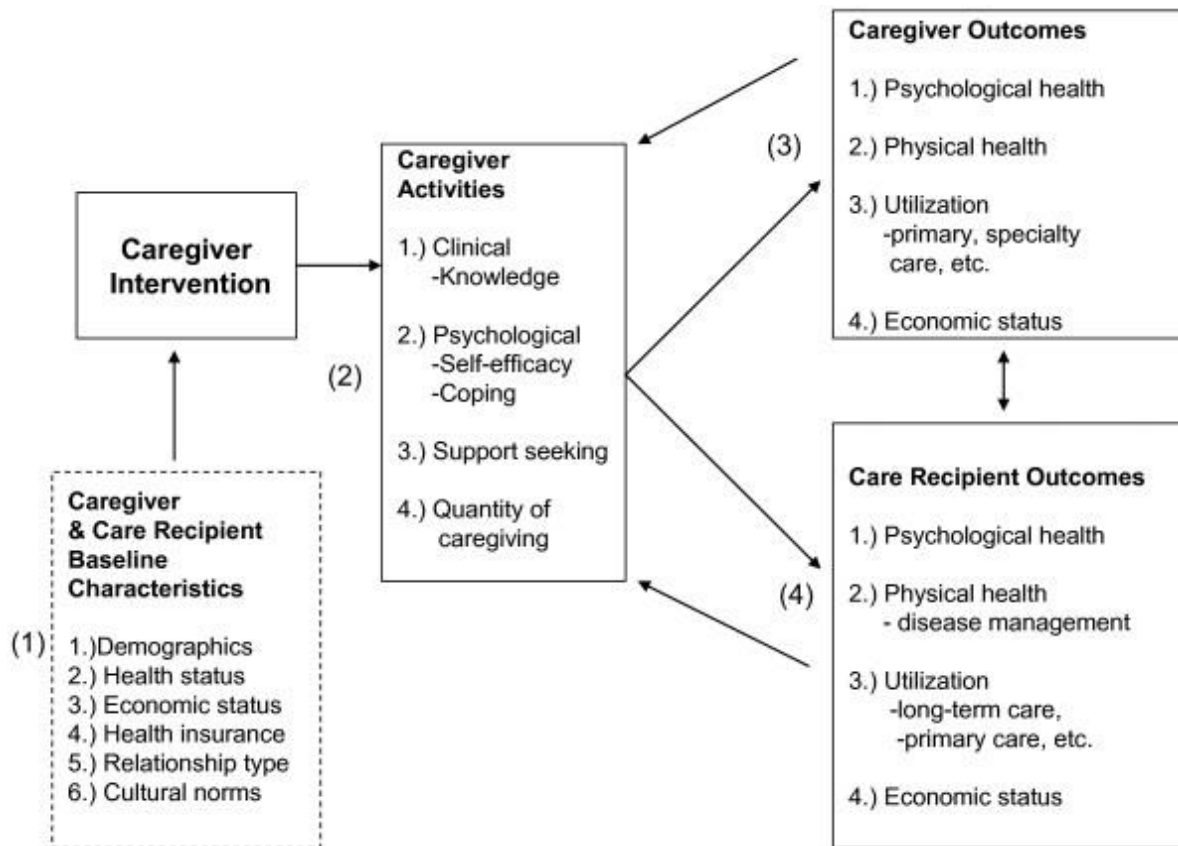
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**Appendix A**

*Figure 1. The Caregiver Burden Intervention Flowchart (Van Houtven, C.H., Voils, C.I. & Weinberger, M., 2011)*



Open Access File: <http://www.biomedcentral.com/1471-2318/11/7>

## Appendix B

Table 1

*Possible Interventions*

- Caregiver assessment to identify high levels of burden (*ZBI -12*).
- Encouraging caregivers to take a break, take care of their own health, maintain a healthy diet, exercise, and seek their own preventive health care: Caregiver's pledge, <https://caregiver.org/caregivers-pledge> (Used with permission of Family Caregiver Alliance, National Center on Caregiving. For more information, visit [www.caregiver.org](http://www.caregiver.org) or call (800) 445-8106).
- Helping caregivers learn to set limits and ask for help. When asked "Is there anything you need?", responding "yes" – I need a meal, I need someone to stay here so I can go out, I need some time by myself, I need some groceries. And, learning to say "no" to requests that are draining rather than nurturing is just as, if not more, important (FCA, 2010).
- Providing information and encouraging support groups (Appendix B, Table 2).
- Providing information on home modification tools, from comprehensive smart home technology to reachers used to pick up items without bending or stretching (Appendix B, Table 2).
- Encouraging families to seek respite/hospice care when needed.
- Helping to identify coping strategies such as praying, talking with friends and family and obtaining additional information from appropriate Web sites (Appendix B, Table 2). The FCA web site includes several general family caregiving resources, state-by-state resources, online support, caregiver education and a chance for caregivers to share their stories (Gaugler, et al., 2014). Another site that offers peer networking, resources and support is the Caregiver Action Network (Appendix B, Table 2).
- Psychoeducation, skills-training and therapeutic counseling interventions for caregivers of patients with chronic conditions such as dementia, cancer, stroke and heart failure.
- Resource/referrals need to be specific and targeted, so as to not overwhelm the caregiver (FCA, 2010).

Table 2

*Possible Resources*

Home modification	<a href="http://www.AbleData.com">http://www.AbleData.com</a>
Caregiver information (general)	<a href="https://caregiver.org/state-list-views?field_state_tid=89">https://caregiver.org/state-list-views?field_state_tid=89</a> . <a href="http://www.caregiveraction.org">http://www.caregiveraction.org</a> <a href="http://n4A.org/about-n4a/?fa=aaa-title-V1">http://n4A.org/about-n4a/?fa=aaa-title-V1</a> <a href="http://www.caregiver.va.gov">http://www.caregiver.va.gov</a> (Veteran specific) <a href="http://www.videocaregiving.org/caregiving.php">http://www.videocaregiving.org/caregiving.php</a> (Video format)
Disease specific advocacy organizations offer up to date resources and information for family caregivers	<a href="http://www.nationalmssociety.org/Resources-support/family-matters">http://www.nationalmssociety.org/Resources-support/family-matters</a> <a href="http://www.theacpa.org">http://www.theacpa.org</a> (chronic pain) <a href="http://www.alz.org">http://www.alz.org</a> <a href="http://www.cancer.org">http://www.cancer.org</a> <a href="http://www.diabetes.org">http://www.diabetes.org</a> <a href="http://www.heart.org">http://www.heart.org</a> <a href="http://lung.org">http://lung.org</a> <a href="http://psychiatry.org">http://psychiatry.org</a> <a href="http://www.strokeassociation.org">http://www.strokeassociation.org</a>
Informational resources	<a href="http://www.nia.nih.gov">http://www.nia.nih.gov</a> <a href="http://www.aarp.org/home-family/caregiving/">http://www.aarp.org/home-family/caregiving/</a>
Decision making tools	<a href="http://decisionaid.ohri.ca">http://decisionaid.ohri.ca</a> <a href="http://www.caregiving.org">http://www.caregiving.org</a> <a href="http://wellspouse.org">http://wellspouse.org</a>
Medicare tools	<a href="http://nihseniorhealth.gov/medicareandcaregivers">http://nihseniorhealth.gov/medicareandcaregivers</a> <a href="http://www.medicare.gov/nursinghomecompare/search.html">http://www.medicare.gov/nursinghomecompare/search.html</a>
Medication tracking tool	<a href="http://www.safemedication.com/safemed/MyMedicineList/MyMedicineList_1.aspx">http://www.safemedication.com/safemed/MyMedicineList/MyMedicineList_1.aspx</a> (Used with permission of ASHP Foundation <a href="mailto:foundation@ashp.org">foundation@ashp.org</a> )
End of life planning	<a href="http://www.agingwithdignity.org/forms/5wishes.pdf">http://www.agingwithdignity.org/forms/5wishes.pdf</a> <a href="http://theconversationproject.org/starter-kit/intro/">http://theconversationproject.org/starter-kit/intro/</a> (Used with permission of <a href="http://IHI.org">IHI.org</a> )
Apps to assist with caregiving	<b>RxMindMe:</b> provides management and reminder alerts for medications <b>Personal Caregiver:</b> options include caring for an aging parent, managing medical conditions, losing weight, and questioning a medical bill <b>iBioMed:</b> extensive care management tools <b>GE MIND (Ipad):</b> interactive modules intended to engage patients and families in creative activities; MIND Facts includes access to learn about the progression of neurologic disorders such as Alzheimer's disease, Parkinson's and stroke. For patients in earlier stages of a disease the <b>MIND AID</b> section offers helpful tips on organizing finances and labeling cabinets (Collier, 2015).

Table 3

*Implementation Plan of Action*

## (a) universal

- caregiver pledge
- <http://www.whatisacaregiver.org/caregiving-for-others.html>
- information about patient's disease process
- information about support groups
- have medications been reviewed and reconciled? Is a medication tracking tool needed?

## (b) selective

- are patient needs identified and symptoms managed to include pain control and pharmacologic interventions as needed for insomnia/dementia?
- are practical supports needed such as domestic/respite care, adult day programs, or food delivery services?
- are there family members/church groups that could be enlisted for help; does the caregiver know how to set limits and ask for help?
- is there technology or home modification tools available to help with patient care
- are referrals needed for visiting nurses, wound care, physical therapy, speech therapy, occupational therapy or social work (available funding)?
- is end of life planning desired?
- is long term placement indicated?

## (c) indicated

- is the caregiver engaging in health promoting behaviors that include exercise or other activities that improve quality of life?
- caregiver referral for psychological supports such as counseling, coping skills, problem solving
- immediate mental health intervention as indicated