Developing gender specific web-based educational modules for caregivers of persons with Alzheimer's disease

Cheryl E. Gies

The University of Toledo

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for Caregivers of Persons with Alzheimer’s Disease

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Dedication

This project is dedicated with love to my wonderful husband Rick, who cares about me and for me, nurtures and completes me in everything I do and in memory of Deb Buchman, forever my mentor, colleague and dearest friend, who urged me to pursue a doctoral degree and carried by her spirit… I did.

I give thanks to you, O Lord, with all my heart (Psalms 138,1).
Acknowledgements

I am deeply grateful for the guidance and support of my project committee, Drs. Linda Pierce, Victoria Steiner, Dianne Smolen and Sherrill Smith. My committee chairs, Drs. Piece and Steiner, thank you for being my captains and compass on this project and for stimulating my interest in caregiver research. Drs. Smolen and Smith, thank you for your role in charting my course. You all made me reach for the stars!! I can honestly say this has been a labor of love. The struggles and frustrations, the discoveries and rewards are valuable lessons. I shall never forget this journey. You are responsible for my growth, development and success! Thank you for taking me onboard.

I do not know where I would be without Phoebe Ballard, the most brilliant Instructional Designer and friend in the world!! Our template could not be better. Thank you for sharing your talent and my enthusiasm. And thank you, Marc Miller for your technology mastery and for answering my million and one silly questions along the way! Without both of you this project could not have sailed forward.

To Bob Hausch and Salli Bollin whose love and enthusiasm for the caregivers of persons with AD is palpable…what a privilege to be welcomed into your world and to work with you.

A heartfelt thank you to Drs. Jane Ransom and Phyllis Gaspar for holding my head above the water … so many times … and to my fellow faculty (you know who you are!) for throwing me a life preserver every now and then.

To my children Eric, Jeremhy and Melissa, their spouses Mike and Mary and my grandchildren Harrison, Sullivan, Violet and Bennett … you always gave me a reason to smile … even when I thought I was drowning!!

To Drs. Margret McFadden, Patricia Carter and Cindra Holland, congratulations … we were all in the boat together and we all made it to shore!!!

I am grateful to all the wonderful caregivers who blessed my life during this project … in your ever-busy lives you found time for this amazing project. Finally, I wish to acknowledge the Rehabilitation Nursing Foundation for generously funding the conversion of the CNA-D instrument to the web-based format.
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Part I: The Evidence-based Practice Project Proposal

Identification of the Problem

The Ohio Department of Aging (ODA, 2007) defines caregiving as any situation where one person helps another person with activities of daily living. Caregivers are persons who provide care for another person and can be either: 1) formal caregivers – persons employed and paid by an agency to provide care or 2) informal caregivers – usually unpaid relatives and non-relatives who provide care (ODA).

The National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) reported in 2009 that there are approximately 66 million informal caregivers in the U.S.; 48.9 million are caregivers caring for adults. Caregivers are described as: 1) predominantly women, 2) age 35 to 64 years, 3) adult children caring for an older person, 4) 45% are college educated, 5) employed and 6) provide care from 1-40 years (NAC/AARP, 2009). Informal caregiver services were estimated at $375 billion per year, a cost that surpassed the annual $158 billion combined cost of nursing home and home health care (Evercare, 2009).

The Alzheimer’s Association (2010) reports that there are 5.3 million people living in the U.S. with Alzheimer’s disease (AD). This number includes 4.9 million people with late onset AD and 200,000 to 500,000 persons who have younger-onset AD (under age 65). The national direct and indirect costs related to AD and other dementias amount to more than $144 billion annually and reflect 12.5 billion hours of care at $11.50 per hour. At least 70 percent of people with AD are living at home, where family members and friends provide most if not all of their care (Alzheimer’s Association).
In the early stages of dementia the informal caregiver may take on relatively simple tasks such as providing transportation and grocery shopping; but as the dementia state advances, the caregiver tasks become more complex. Later stage dementia responsibilities usually include medication and treatment administration or complex safety and behavior management. The informal caregiver eventually becomes responsible for the majority of care, performing tasks that are physically, emotionally, socially and financially demanding (Thompson, Spilsbury, Hall, Birks, Barnes & Adamson, 2007). Eventually, the caregiver is the primary resource not only for the person with dementia but also for the health care system. Caregivers can become the hidden patients who experience emotional distress, depression, poor health, fatigue, financial burden, and a higher rate of mortality compared with non-caregivers (Ory, Hoffman, Yee, Tennstedt, & Schultz, 1999).

Future population projections suggest that families will continue to be the principal source of support for persons with dementia and that the home will remain the predominant setting for dementia care (Czaja, Eisdorfer, & Schulz, 2000; Family Caregiver Alliance (FCA), 2005; Wahl & Gitlin, 2003). Unfortunately, caregivers’ lack of “formal status within the health care system” prevents the system from responding to their unmet needs for “support, respite, information and advocacy” (Guberman, Keefe, Fancey, Nahmiash, & Barylak, 2001, p. 9). American caregivers are rarely integrated into assessment procedures for programs that serve the frail elderly or the disabled (FCA, 2005). It is prudent for healthcare providers to consider both the caregiver and the care receiver’s unique relationship when planning and rendering healthcare.
Recent studies on caregivers’ problems, needs and experiences reveal differences that may be gender based, requiring gender specific interventions (Bedard, Kuzik, Chambers, Molloy, Dubois, & Lever, 2005). Female caregivers of persons with dementia internalize stress and experience more caregiver burden, depression, and poorer health than males (Luchetti, Uhummwangho, Dordon, Lorido, Barbieri, Bolognesi et al., 2009; Papastravrou, Tsangari, Kalokerinou, Papacostas & Sourtzi, 2009; Pinquart & Sorensen 2006); whereas, male caregivers tend to cope with caregiving stress using strategies based on their “sense of selves as men and their attempt to take it like men” (Calasanti & King, 2007, p. 527). Cultural differences and healthcare practitioner expectations also add to caregivers’ response to the problems and burden of long-term care (Chiou, Chen & Wang, 2005; Guberman, Lavoie, Pepin, Lauzon, & Montejo, 2006; Rabinowitz, & Gallagher-Thompson, 2007; Sugiura, Ito, Kutsumi & Mikami, 2009).

Interventions (such as support groups and carer training) aimed at supporting and/or providing information to caregivers of persons with dementia have varying effects on individual caregivers (Thompson et al., 2007); therefore, matching intervention strategies that target specific caregiver populations (gender) may be beneficial (Gitlin, Burgio, Mahoney, Burnes, Zhang, Schulz et al., 2003). During the last five years, the demand for caregiving information among caregivers in high burden situations has increased, especially in areas of care recipient, safety at home, easy activities and decisions about home care agencies, assisted living facility or nursing home placement (NAC/AARP, 2009). Caregivers rated healthcare providers (36%) and the Internet (25%) as their top resources for retrieving information about caregiving problems and needs (NAC/AARP).
Internet technology offers “great promise for facilitating some of the responsibilities that caregivers shoulder and more generally to improve the care of their recipients” (NAC/AARP, 2009, p. 20). Internet technology offers practitioners the ability to integrate evidence based practice guidelines into education and support programs for persons with dementia and their caregivers. These web-based programs are proving to be an efficient, cost effective, and convenient intervention strategy to meet the problems and needs of patients and their families (Beauchamp, Irvine, Seeley, & Johnson, 2005).
Theoretical Framework

Identifying and applying an appropriate theoretical framework to a nursing evidence-based project provides organization and structure. The Framework of Systemic Organization (Friedemann, 1995; 2010) focuses on the human system. This theory frames the imbalance and discord long-term caregivers of persons with dementia can experience and is applicable and relevant to guiding this evidence-based practice (EBP) nursing project.

The Framework of Systemic Organization

The Framework of Systemic Organization (Friedemann, 1995; 2010) is a nursing systems theory that focuses on the family. All elements of the system seek congruence to maintain optimal health. Friedemann (1995; 2010) maintains that the energy balance flowing freely among and between human systems is congruence. Process dimensions strive toward abstract System Targets to maintain a healthy congruent system. The framework applies to the internal system within an individual and to external systems that include the individual such as a family system. The system is able to function at optimal level when there is congruence. Imbalance in one area creates tension and stress for the rest of the system. The schematic (Figure 1) illustrates how the human system is organized to “buffer anxiety and attempt congruence” (Friedemann, 1995, p. 6). The arrows are used to display the rhythms and patterns of energy flow and the connectedness of a balanced system as a whole.

Process dimensions. Process dimensions are behavior strategies or how a person or a family seeks to equalize life stressors or problems (Friedemann, 1995; 2010). The process dimensions are part of the inner core of the systemic organization framework.
System maintenance focuses on elements that protect, maintain and defend the system. System maintenance is directed at the system targets of stability and control. System change is an independent dimension where actions within this system center on a person’s interpretation of internal or environmental pressure and lead to targets of control and growth. A person has to decide to change in order to adapt to the pressure. Coherence maintains unity and targets stability and spirituality. Individuation targets spirituality which links a person to other systems requiring coherence, seeking connectedness and eventually leading to growth (Friedemann, 1995; 2010). These process dimensions can be assessed through the nursing process. The nursing process fits well within these dimensions as nursing seeks to identify and resolve disruption or incongruence within individual and family systems through assessment, care planning, intervention and evaluation.

System targets. Four system targets (control, spirituality, stability and growth) constantly interact with each other seeking equilibrium to maintain a healthy
DEVELOPING GENDER SPECIFIC WEB-BASED

system internally (self) and externally (environment) (Friedemann, 1995; 2010). The first system target is control which reduces anxiety or stress or buffers problems by blocking change or utilizing knowledge and information to facilitate change. The second system target is spirituality which supports connectedness and order in the universe to ward off helplessness. The third system target of stability is based on personal values, attitudes and rules and is as essential for system survival as the fourth system target growth. Growth occurs during imbalance in the system, that is, incongruence, when stability is no longer compatible with the environment and change is required in order for the system to survive (Friedemann, 1995; 2010).

The framework of systemic organization can be used to understand the complexities of long term caregiving and the changes that occur in congruence for “families in terms of their specific life process and relationships with the patient” (Friedemann, 1995, p. 266). Even though most caregivers of AD persons are women who are related to the care receiver, male caregivers are just as vulnerable to system incongruence. The long-term consequences of caregivers’ problems in caring strain the family system as responsibilities mount, and personal freedom and opportunities for care of self dwindle. Loss of control and stability, conflict with personal values and beliefs and the need to grow to a “new normal” create an incongruent state resulting in feelings of burden, stress and anxiety for the caregiver. Freidemann (1995) describes this situation as a “crisis” state (p. 273; see Figure 2) where “change is overwhelming and uncontrolled…and instead of adjusting to it” all the caregiver’s energy is focused on system maintenance and individuation is blocked (p. 274). Understanding the uniqueness of each caregiver/care recipient relationship and identifying appropriate interventions are
vital components in restoring congruence to the caregiving situation (p. 273; see Figure 3).

Figure 2. Caregiver Crisis State

Figure 3. Caregiver Congruent State

The Framework of Systemic Organization Application

Restoring congruence is operationalized by stabilizing the internal system of the caregiver and the external system of the family. The Framework of Systemic Organization (Friedemann, 1995; 2010) is incorporated into a schematic and reflects the author’s interpretation of adding an intervention to restore some congruence in an incongruent caregiving situation (see Figure 4). Although a review of the literature discussed later in this paper cites several interventions that address the problems/needs of caregivers, the present project focuses on only one aspect of caregiver support and that is education delivered via the Internet. Web-based education modules specific to gender, may be a unique way to introduce new information into a caregiving situation and thereby promote individuation (Friedemann, 1995; 2010). Developing targeted gender specific web-based educational modules to help caregivers cope with identified caregiver problems/needs is the focus of this project.
Figure 4. Evidence-Based Practice Project schematic: Restoring congruence in caregivers of persons with AD using Web-based educational modules to promote Individuation.
Evidence-Based Practice Model

The Stetler Model of Evidence-based Practice is used to organize the “five categories or phases of activity” for this project (Melnyk & Fineout-Overholt, 2010, p. 247). The five phases are: 1) preparation, 2) validation, 3) comparative evaluation/decision making, 4) translation/application and 5) evaluation.

In the first phase of preparation, the practitioner identifies a practice or population need and searches for relevant research evidence to gain in depth understanding of the need. In the second phase, validation, the practitioner reviews, critiques, and summarizes the usefulness of the collected evidence. Comparative evaluation and decision making is the third phase, which involves choosing how to use and apply the evidence to the identified need, followed by the fourth phase of translation/application when a project is implemented to promote a change or make improvement. The fifth phase is evaluation. During this final phase the practitioner determines whether the goals of the project are met, identifies areas for improvement and disseminates project findings to associated practice groups and systems.

The first two phases of the Stetler Model (preparation and validation) are completed in Part I of this EBP project proposal to develop gender specific WBEMs for caregivers of persons with AD. Phases three through five (comparative evaluation/decision making, translation/application and evaluation) are completed in Part II of the project. An overview of the project planned activities is presented in Table 1.
## Action Plan

**Table 1**

_Evidence-Based Practice Project Action Plan_

<table>
<thead>
<tr>
<th>Stetler Model of EBP (Phases 1-5)</th>
<th>Activities to complete</th>
<th>Person(s) accountable</th>
<th>Timeline Projected/Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 1: Preparation</strong></td>
<td>Identify if there are gender differences in the problems reported by caregivers of persons with dementia</td>
<td>Cheryl Gies, Linda Pierce, Victoria Steiner, Dianne Smolen</td>
<td>Projected 02/00/10 Actual 02/00/10</td>
</tr>
<tr>
<td>Objective: Identify Topic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Objective: Form Team</td>
<td>Invite team members and form DNP project committee</td>
<td>UTCON, Cheryl Gies, Linda Pierce, Victoria Steiner, Dianne Smolen, WSUCON, Sherrill Smith</td>
<td>Projected 04/00/10 Actual 05/00/10</td>
</tr>
<tr>
<td><strong>Phase 2: Validation</strong></td>
<td>Begin Literature Review, Review study findings, Organize literature, Submit first draft of EBP project proposal</td>
<td>Cheryl Gies</td>
<td>Projected 06/30/10 Actual 07/07/10</td>
</tr>
<tr>
<td>Objective: Find Evidence</td>
<td>Review and make revisions to second draft of EBP project proposal</td>
<td>Cheryl Gies, Linda Pierce, Victoria Steiner</td>
<td>Projected 07/12/10 Actual 07/13/10</td>
</tr>
<tr>
<td></td>
<td>Review and make revisions to third draft of EBP project proposal</td>
<td>Cheryl Gies</td>
<td>Projected 07/19/10 Actual 07/21/10</td>
</tr>
<tr>
<td></td>
<td>Submit EBP project proposal to DNP chair and committee</td>
<td>Cheryl Gies, Linda Pierce, Victoria Steiner</td>
<td>Projected 08/02/10 Actual 07/31/10</td>
</tr>
<tr>
<td></td>
<td>Defend EBP Project proposal</td>
<td>Dianne Smolen, Sherrill Smith</td>
<td>Projected 08/16/10 Actual 08/16/10</td>
</tr>
<tr>
<td><strong>Phase 3: Comparative Evaluation / Decision Making</strong></td>
<td>Identify caregiver sites for data collection: Local Caregiver Care Conference, UT Geriatric Center, Local Alzheimer Association, Secure IRB approval for caregiver assessment enrollment and Caregiver Evaluation Questionnaire</td>
<td>Cheryl Gies, Linda Pierce, Victoria Steiner, Cletus Iwuagwu, Salli Bollin</td>
<td>Projected 06/00/10 Actual 06/00/10</td>
</tr>
</tbody>
</table>
Table 1 (continued)

**Evidence-based Practice Project Action Plan**

<table>
<thead>
<tr>
<th>Stetler Model of EBP (Phases 1-5)</th>
<th>Activities to complete</th>
<th>Person(s) accountable</th>
<th>Timeline Projected/Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Phase 3:</strong></td>
<td>Complete DNP committee suggested manuscript revisions; Consider planned data analysis, evaluation and module template</td>
<td>Cheryl Gies Committee</td>
<td>Projected 08/15/10 Actual 09/16/10</td>
</tr>
<tr>
<td>Objective: Critique Literature</td>
<td>Begin collaboration with UT instructional design and technology experts for module development and use of ECHO 360</td>
<td>Sherrill Smith Phoebe Ballard Marc Miller</td>
<td></td>
</tr>
<tr>
<td><strong>Phase 4:</strong></td>
<td>Complete caregiver assessments and compare to literature review Determine key male and female topics; begin web-based education module development – design, content, experts for module presentations</td>
<td>Cheryl Gies Sherrill Smith Phoebe Ballard</td>
<td>Projected 10/30/10 Actual 11/00/10</td>
</tr>
<tr>
<td>Translation/application</td>
<td>Finalize module template ECHO 360 software orientation; Develop 2 male and 2 female presentations; review associated, credible web links Trial modules with caregiver volunteers (6 male &amp; 6 female</td>
<td>Cheryl Gies Phoebe Ballard Marc Miller</td>
<td>Projected 12/01/10 Actual 01/15/11</td>
</tr>
<tr>
<td>Objective: Implement Project</td>
<td>Analyze results/findings of caregiver evaluation questionnaires of the Web-based education modules</td>
<td>Salli Bollin</td>
<td>Male 12/06/11 Female 02/02/11</td>
</tr>
<tr>
<td><strong>Phase 5:</strong> Evaluation</td>
<td>Identify and discuss project findings and conclusions</td>
<td>Cheryl Gies Linda Pierce Victoria Steiner</td>
<td>Projected 12/01/10 Actual 02/14/11</td>
</tr>
<tr>
<td>Objective: Evaluate and Disseminate Findings</td>
<td>Prepare and present EBP project poster at MNRS</td>
<td>Cheryl Gies</td>
<td>Actual 03/01/11</td>
</tr>
<tr>
<td></td>
<td>Submit EBP Project final manuscript to DNP chair and committee</td>
<td>Cheryl Gies</td>
<td>Projected 04/04/11 Actual 04/04/11</td>
</tr>
<tr>
<td></td>
<td>Defend EBP project</td>
<td>Cheryl Gies</td>
<td>Projected 04/19/11</td>
</tr>
<tr>
<td></td>
<td>Present EBP project poster at UTCON Research Day</td>
<td>Cheryl Gies</td>
<td>Projected 04/25/11</td>
</tr>
</tbody>
</table>
Table 1 (continued)

Evidence-based Practice Project Action Plan

<table>
<thead>
<tr>
<th>Stetler Model of EBP (Phases 1-5) Project Objectives</th>
<th>Activities to complete</th>
<th>Person(s) accountable</th>
<th>Timeline Projected/Actual</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Submit final manuscript revisions to DNP Chair and committee</td>
<td>Cheryl Gies</td>
<td>Projected 04/30/11</td>
</tr>
<tr>
<td></td>
<td>Publication in peer reviewed journal</td>
<td></td>
<td>Actual 04/30/11</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Projected 2012</td>
</tr>
</tbody>
</table>
Review of the Research Literature

This evidence-based project proposal is comprised of two phases. Phase I will identify if there are gender differences in problems/needs of caregivers of persons with AD in the research literature. Phase II will compare the literature findings to the results of an assessment of problems/needs of a group of AD caregivers in northern Ohio. The findings will be used to guide the development of gender specific targeted web-based educational modules focused on the identified key male and female problems/needs areas.

Search Strategy

Repeated searches of the National Library of Medicine's bibliographic database (MEDLINE), the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and the United States National Library of Medicine (PubMED) databases were completed during an eighteen month period beginning in 2009 using key words: caregivers, caregiver assessment, Alzheimer’s disease, dementia caregivers, gender differences, caregiver interventions, web-based education, web-based interventions, evidence-based interventions, and advanced practice nursing.

The searches focused on caregivers of persons with dementia to identify: 1) research literature about caregivers’ problems and needs, caregiver gender differences, and caregiver assessment and 2) evidence-based practice guidelines and protocols and interventional strategies, specifically Internet education, to assist caregivers to cope with their problems. The results of this search, including the review of the literature and the level of evidence for each study, are presented in Appendix A.
There are six levels of quantitative evidence described by Levin, Singleton and Jacobs (2008): Level I (strongest level of evidence) are systematic reviews (integrative/Meta-analysis/clinical practice guidelines based on systematic reviews), Level II are single experimental studies (RCT), Level III are quasi-experimental studies, Level IV are non-experimental studies, Level V are case report/program evaluation/narrative literature reviews and Level VI are opinions of respected authorities (p. 198). Qualitative studies are not included in this hierarchical schema but are included in a Johns Hopkins schema that ranks qualitative studies at the same level as non-experimental studies (Level IV) (Newhouse, Dearholt, Poe, Pugh & White, 2007). Therefore, qualitative studies in Appendix A are rated as Level IV. The studies discussed in the narrative portion of the review of the literature are the studies that are relevant to this project.

**Literature Review**

The literature review includes five sections: 1) caregiver problems/needs, 2) caregiver gender differences, 3) caregiver assessment, 4) caregiver interventions, and 5) web-based education.

**Caregiver problems/needs.** Four studies are identified and address caregiver problems/needs. The first study is a recent randomized quantitative telephone interview study conducted in the United States (U.S.) by the National Alliance of Caregivers and the American Association of Retired Persons (NAC/AARP, 2009), caregivers ($n = 1480$) and caregivers of persons 50 years and older ($n = 288$) were surveyed concerning 22 aspects of caregiving. Fourteen caregiver information and support needs were reported. The top five information needs were: 1) care recipient home safety, 2) managing
emotional/physical stress, 3) easy care recipient activities, 4) finding personal time, and 5) balancing work/family responsibilities. The next six through ten needs were: 6) talking to healthcare professionals, 7) choosing home care agency, 8) end of life decisions, 9) assisted living information and 10) managing challenging behaviors. The final four needs were: choosing a nursing home, moving/lifting the care recipient, managing incontinence and non-English educational materials. Aside from a non-experimental design, no study limitations are identified (NAC/AARP, 2009).

The second study is a survey conducted to identify the information and support needs of family caregivers of persons with AD or related dementia (n = 128) using databases “maintained by the adult daycare program of the Lexington/Bluegrass Chapter of the Alzheimer’s Association and the memory disorders clinic of the University of Kentucky’s Alzheimer’s Disease Research Center” (Wackerbarth & Johnson, 2002, p. 96). Overall, the two most important information needs identified were: 1) health plan coverage and 2) how to find the best care. Independent t-tests were used to compare male and female group means. The study reported that some information is important to most caregivers while other information and support needs are gender, residence or experience specific. Female caregivers for instance, rated two needs higher than male caregivers: 1) “interacting with and supporting others” and 2) “finding support for myself” (p. 98) while experienced caregivers rated legal and financial information higher than novice caregivers. In general, the caregivers rated information needs a higher priority than support needs. Several limitations that would reduce generalizability of the study findings were identified: all participants were Kentuckians, potential responder
bias, subjective judgment for qualitative coding and the high education level and high support service use of the respondents (Wackerbarth & Johnson).

The information and service needs of persons with mild to moderate dementia \((n = 100)\) and their caregivers \((n = 100)\) living in rural communities were identified in a third study through a self-report survey (Edelman, Kuhn, Fulton & Kyrouac, 2006). The participants were recruited from an outpatient clinic. Data were analyzed using the Statistical Package for the Social Sciences (SPSS). The study illustrated caregivers’ need for basic information and services on a variety of topics even though there was a lapse of two years from the original diagnosis of AD. The top five areas of caregiver interest were: 1) legal and financial planning, 2) dealing with family and friends, 3) long-term care, 4) genetic aspects of AD and 5) alternative medicine or treatment for memory loss. The authors stated the importance of clinicians’ continual reassessment and communication to address the changing needs of both care receivers and caregivers. Study limitations identified by the authors were the cross sectional design, rural sampling and almost exclusive white/non-Hispanic and a well educated sample population (Edelman et al., 2006).

Identifying the most pressing problems of dementia caregivers was the focus of the forth study, a secondary analysis of data collected at the Memphis site of the REACH study (Nichols, Martindale-Adams, Burns, Graney & Lummus, 2006). Caregivers \((n = 165)\) were recruited from 14 physician offices and chose their own education topics. Study participants received either a behavior care management intervention \((n = 77)\) or an enhanced care management intervention (behavior care management plus stress and coping and improving caregiver well-being intervention; \(n = 88)\). In the behavior care
management intervention, the four most requested topics were: activities, combativeness, communication and confusion. Of interest, men had higher interest then women in healthy lifestyle and help with care recipient eating. In the stress and coping intervention the four most requested topics were: healthy lifestyle, grief, relaxation and caregiver depression. The authors reported that caregiver needs were related to the stage of dementia – the later the stage of dementia the greater the variety of requested topics and “clinical characteristics of both the caregiver and the care receiver appear(ed) to influence selection of educational (topic) areas for the caregiver” (p. 12). Promoting interventions in the primary care setting may improve clinical outcomes, achieve the best educational results (i.e. take advantage of a teachable moment) and be cost effective. The authors reported three study limitations: 1) clinical rather than statistical significant findings, 2) potential for artificially inflated topic choices and 3) participants were experienced caregivers of significantly cognitively impaired care recipients (Nichols et al., 2006).

**Caregiver gender differences.** Gender differences may impact caregiver problems/needs. Several caregiver gender differences studies are reported in the literature and nine are discussed in this section. Two studies focus on the caregiver population in general, two are international dementia caregiver studies and four studies and one meta-analysis are dementia caregiver studies from the U.S. and Canada.

Two gender differences studies on caregivers in general, reported that female caregivers had more negative health problems than males, provided more care, and reported more stress and burden than male caregivers (Chiou et al., 2005; Navaeie-Waliser, Spriggs & Feldman, 2002). In the first study, Chiou et al., examined family caregivers (280 females and 108 males) of incapacitated family members in Taiwan using
the 12 item Chinese Health Questionnaire to examine if differences exist between male and female caregivers. ANCOVA analysis was performed to analyze data. The results indicated a need to recognize the value of caregiving in the Taiwanese society and caregiving can be complicated by cultural and social expectations (Chiou et al., 2005). The gender differences reported in this study were limited to the Taiwanese caregivers and results may not be generalized to other ethnic populations.

In the second study, Navaeie-Waliser et al., (2002) completed a national telephone interview of informal caregivers ($n = 1002$) in Chicago, Illinois. Sociodemographic, physical, emotional health characteristics, caregiving type and intensity, formal care support, care provision problems, unmet needs, coping strategies and care recipients’ health and relationship to caregivers were examined between genders using descriptive and multivariate analysis. Women caregivers were found to be under more stress, provided a large volume of care with little support from formal caregivers. The investigators recommended program planners work to provide support services to reduce family strain such as skill training, support groups and respite services. Suggestions included helping caregivers handle negative emotions, teaching caregivers how to view their role in a more positive light and participation in support groups. The authors stated that “interventions need to be gender sensitive because…even the language used by service providers is especially important if interventions are to be effective” (Navaeie-Waliser et al., 2002, p. 1258). Three limitations were reported: 1) the study was vulnerable to non-sampling errors, 2) cognitive function, co-morbidities and race/ethnic differences were not considered and 3) the response and cooperation rates were not optimal.
Two international dementia caregiver studies focus on caregiver problems and needs. The first international descriptive correlation study conducted in Italy recruited AD caregivers \((n = 99)\) from a cognitive disorders clinic (Luchetti et al., 2009). The purpose of the study was to identify how caregiver burden was influenced by caregiver and care receiver characteristics and social support. Caregiver burden, demographics, social support (formal and informal), support group attendance and care receiver characteristic data were collected. SPSS software was used to analyze data, ANOVA and multiple statistical comparisons were applied. Results indicated that burden was related to restriction in personal time and a sense of failure about hopes and expectations. Women reported more burden than men and suffered more fatigue and poorer physical health. The lack of a comparison group and the non-randomized convenience sample were cited as limitations for this study (Luchetti et al.).

The second international cross-sectional study conducted in Cyprus, explored gender differences in caregiving and its consequences of burden, psychiatric morbidity and coping with the challenges for primary caregivers of persons with dementia (Papastravrou et al., 2009). Participants \((n = 172)\) responsible for care of a person with dementia for at least one year were recruited from neurology clinics in Cyprus and completed a questionnaire that included the Memory and Behavior Problem Checklist, the Zarit Burden Interview, the CES-D and the Ways of Coping Questionnaire. Questionnaire data were analyzed using independent samples \(t\)-tests, one-way ANOVA, chi-square, and factor analysis. Several important findings were identified in this study: 1) women seek more social support, 2) women used denial strategies more than men, 3) women are burdened more by patient’s emotional problems and disorientation; whereas,
men have more difficulty with activities of daily living and conflicting demands on their time, 4) women use emotional coping strategies such as wishful thinking and day dreaming which are less effective in managing stress, 4) men use mechanisms that create a psychological distance from the care receiver and rational, detached coping styles 5) there was no reduction in burden whether the patient was cared for at home or in an institution and 6) females were more at risk for negative consequences of caregiving.

Although no study limitations were reported, there may be some geographical and cultural bias represented that could limit generalizability to caregivers in other countries (Papastravrou et al.,).

Four studies and one meta-analysis were conducted in the U.S. and Canada. A study of Alzheimer disease primary caregivers (n = 557) of Canadian community dwelling persons referred to a memory clinic examined why women caregivers reported more burden than men caregivers and the impact care receiver’s problem behavior had on a sense of burden (Bedard, et al., 2005). Clinical Nurse Specialists assessed caregivers using a variety of reliable, valid instruments to examine care receiver function, caregiver attributes, external supports and caregiver burden. Data were analyzed using ANOVA, Chi-square, Mann-Whitney and Kruskal-Wallis, and Hierarchical regression model procedures. Women caring for men had higher burden scores, and care receiver behaviors such as anger and physical threat were more of a concern for women caregivers than for men caregivers. The investigators concluded that male and female caregivers of persons with AD may experience different role burden in identical circumstances and require gender specific interventions; furthermore, the investigators surmised that women report excess burden because they are faced with a different, difficult sets of
circumstances and the expectations placed on women caregivers put them at a disadvantage. Problem focused strategies and interventions directed at reactions to problem behaviors such as those outlined in the California Workgroup on Guidelines for Alzheimer’s disease Management (2008) were suggested. The select group of caregivers in this study limited generalizability of the findings and there were limited data available on caregiver attributes and external supports (Bedard et al., 2005).

A small U.S qualitative study by Calasanti and King (2007) analyzed spousal caregivers \( n = 22 \) of persons AD in the U.S. Participants were recruited and interviewed through formal agencies and support groups. Data were collected and analyzed in an iterative process using QSR NUD*IST 6.0 to examine themes and their relationship to one another. The investigators reported that husbands and wives seem to have the same sentiments when performing similar caregiving tasks; however, male caregiving is rooted in a “sense of selves as a man” (p. 516). Men tended to exert more force, focus on tasks, block emotions, minimize disruptions, use distraction, and self medicate during caregiving situations. While men used control tactics that mimicked their work history experiences, women caregivers were reluctant to “diminish their husbands’ sense of control” (p. 525). Although spousal caregivers seek stress relief, they may resist interventions that interfere with their traditional ideals of gender and ultimately their sense of identity. This study was limited to spousal caregivers and this should be considered when interpreting the findings (Calasanti & King, 2007).

Female caregivers were found to experience more stress, depression, caregiver burden, anxiety, hostility, and physical symptoms than men in a U.S study of spousal caregivers of persons with AD (45 female; 16 male) in large metropolitan areas in Texas.
and New Mexico (Thompson, Lewis, Murphy, Hale, Blackwell, Acton et al, 2004). Reliable, valid questionnaire instruments were used for data collection. The 2002 Statistical Package for the Social Sciences (SPSS) was used for data analysis. Differences were identified in the way men and women are affected by the experience of caregiving. Men and women approach caregiving differently; women identify with the caregiving role while men view caregiving as a task to complete. Male caregivers were found to have higher Sense of Coherence (SOC) scores. High SOC scores are associated with personality characteristics that promote stress resilience. Convenience sampling was a limitation in this study (Thompson et al., 2004).

An early U.S. study by Ford, Goode, Barrett, Harrell and Haley (1997) reported that gender roles were less important in terms of stressfulness than the nature of the stressor; caregiver distress was greater for dangerous behavior and aggression. Caregivers of AD patients (male = 76; female = 130) were recruited from a memory disorder clinic at the University of Alabama at Birmingham (UAB). Participants were given lengthy interviews and completed a comprehensive questionnaire to assess the subjective stressfulness of 44 common caregiving task problems encountered during care of a person with dementia. Gender differences in problem occurrence were analyzed through Chi-Square and t tests to determine the stressfulness of individual items. The ten most stressful problems were associated with behavior problems (dangerous behavior, wandering, embarrassing behavior, wakes caregiver, agitation, suspicious/accusative, anger, sad or depressed affect, trying to hit) followed by repetitive questioning. Only “laundry and patient transfer revealed greater appraised stressfulness for males” and approached gender difference significance (p. 164). Clinician planned interventions such
as “improving caregivers’ tolerance for…stressful problems” (p. 164) were recommended to assist caregivers deal with aggressive and dangerous behaviors to reduce caregiver distress. Reliance on caregivers’ reports of the prevalence of behavioral problems was noted as a methodological limitation in this study (Ford et al.).

Pinquart and Sorensen (2006) completed a meta-analysis of 229 studies “on gender differences in caregiver psychological and physical health, caregiving stressors, and social resources” (p. 33). Small gender caregiver differences in three caregiving variables - psychological health, physical health, and caregiving stressors were reported. Statistically reliable gender differences were identified in that, women experienced higher levels of burden and depression and had lower levels of health and well-being than men; furthermore, women provided more hours of care and were more likely to care for persons with behavioral problems. Five conclusions were drawn from this analysis: 1) gender specific caregiver interventions should be tailored to negative caregiver outcomes (burden, depression, amount of care provision, and caregiver-care receiver relationship quality), 2) there are gender differences in depression and physical health because women have more caregiver stressors, 3) gender differences in peer-reviewed studies may be over-estimated because study results that do not report strong gender differences are “more difficult to get published” (p. 39), 4) caregiver gender differences are subject to social change and 5) husbands’ and wives’ caregiving experiences are more similar than sons’ and daughters’ caregiving experiences. Study limitations included: heterogeneous bivariate effect sizes, limited number of studies available for some variables to be included in the meta-analysis, other sample characteristics could have influenced the size
of the gender differences in caregiving and the increased possibility of Type I error based on a search for 12 variables’ moderators (Pinquart & Sorensen).

**Caregiver assessment.** Caregiver assessment is defined as “a systematic process of gathering information about a caregiving situation and identifying the particular problems, needs, resources, and strengths of the family caregiver” (Feinberg, Wolkwitz & Goldstein, 2006, p. 7). The goal of caregiver assessment is the development of an individualized plan of care to meet the support and service needs of the caregiver. Although caregiver assessment is viewed as important by many healthcare professionals, a review of the literature reveals a paucity of caregiver assessment research studies. Caregiver assessment is not standardized nor is it shared among healthcare disciplines. A summary of caregiver assessments can be found in Appendix B.

Caregivers are not routinely integrated into assessment procedures for care receivers and while caregiver presence may be noted at times during assessment “no follow-up examines the caregiver’s own limitation, abilities, and desires for support” (FCA, 2006, p.102). There are no assessment instruments specific to caregivers of persons with dementia in the U.S. even though these caregivers are prone to higher levels of depression and emotional problems than non-caregivers (Feinberg et al, 2006) and their needs and challenges are often unique.

Three barriers to conducting caregiver assessment have been identified: 1) lack of recognition of the caregiver as a patient, 2) lack of consensus on what components should be included in a caregiver assessment, and 3) lack of funding and reimbursement for caregiver assessment (Feinberg et al., 2006). Current guidelines recommend multidimensional caregiver assessment (reflecting areas that place caregivers at most
risk), driven by a conceptual framework, culturally relevant and easy to administer (Czaja, Gitlin, Schultz, Zhang, Burgio, Stevens et al., 2009).

In the U.S. the concept of caregiver assessment has been slow to gain momentum. Only four states: Massachusetts, Minnesota, Pennsylvania and Washington include a caregiver assessment component in their home and community-based care recipient assessment procedures. Only one state, California, reports a standardized caregiver assessment focused solely on the caregiver.

A recent U.S. study using data from the REACH II trial investigators used conceptual and psychometric analyses to develop and validate a 16-item screening measure (not included in Appendix B), the Risk Assessment Measure (RAM), to assess well-being and identify support needs for family caregivers of persons with dementia ($n = 642$) (Czaja, et al., 2009). The six assessment domains associated with caregiver risk and amenable to intervention were: depression, burden, self-care, and health behaviors, social support, safety and patient problem behaviors. Education and information were listed as treatment strategies for all six domains. The RAM had acceptable internal consistency for a multidimensional scale and concurrent validity was demonstrated with promise for its use in a variety of healthcare settings with an administration time of 5-7 minutes. The investigators emphasized that a successful care plan for an AD person “rests largely on the caregiver, (and) effective care outcomes depend on understanding the needs and risks of both the caregiver and patient” (Czaja et al., p. 1071). Lack of assessment domains for financial strain or social activities were determined to be instrument limitations.

The American Medical Association developed a Caregiver Self-Assessment questionnaire that is self-administered and caregiver-focused. It has 18 items to assist
health care professionals in primary care recognize and arrange support for family caregivers (AMA, 2009). This questionnaire is a screening tool that can be used as an index for caregiver distress; but, it is not a comprehensive assessment tool and not widely used in primary care.

There are two international caregiver assessment instruments: 1) the Caregivers Aspirations, Realities, and Expectations (C.A.R.E.) Tool (Guberman et al., 2001) and 2) the Carers’ Needs Assessment for Dementia (CNA-D) Instrument (Wancata, Krautgartner, Berner, Alexandrowicz, Unger, Kaiser et al., 2005).

The C.A.R.E. Tool evolved in response to growing concerns for caregivers’ well-being and the need for a validated, comprehensive assessment instrument in North America to assess caregivers (Keefe et al., 2008). The C.A.R.E. Tool contains 10 sections that cover different aspects of a caregiver’s situation: demographic information of the caregiver and care receiver, caregiving work, informal and formal support, living arrangements, other responsibilities, financial contribution, physical and emotional health, family relations, crisis and long term planning, and service support needs. The tool is not specific to dementia caregivers.

The results of three research studies completed using the CARE Tool were summarized in one report (Guberman, Keefe, Fancey & Barylak, 2007). The first study (2001) by the authors involved tool development and validation. Study participants included seven home care agencies, caregivers of home care patients (n = 168), seven focus groups with assessors (n = 40) and seven interviews with managers. The second study (2003) evaluated the impact of using the assessment instrument on the caregivers. The sample included different home care agencies in three regions (n = 10), six focus
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groups, and seven practitioner and manager interviews. This study included caregiving situations of persons with and without dementia. The third study (2006) was conducted to gain understanding concerning barriers to implementing caregiver assessment. The sample informants included: caregivers, practitioners and managers \((n = 24)\) (Guberman et al., (2007).

The authors combined the results from the three studies in a summary report of findings because similar themes for successful implementation of the C.A.R.E. Tool were identified. The themes were: 1) classification of caregiver status, 2) explicit agency philosophy regarding family care roles and responsibilities and assessment and 3) agency buy-in. Issues for implementation included: 1) integrating the C.A.R.E. Tool with other assessment tools, 2) training and supervision, organization and resources for assessment and 4) logistical questions. The authors reported the limitations in these studies were the lack of examining the instrument in daily practice and that conclusions were based on participant perception of what helps or hinders assessment (Guberman et al., (2007).

The C.A.R.E. Tool was tested in one study involving caregivers of persons with dementia (Keefe et al., 2008). The study goal was to evaluate the impact the assessment findings had on promoting changes in caregiving situations, caregiver well-being and home care services. Study participants \((n = 349)\) included caregivers of persons with and without Alzheimer Disease; half of the group were assessed and the other half of the group were not assessed. The assessed caregivers reported more recognition and awareness from service providers, there were no significant differences in well-being between groups and practitioners reported improved understanding of “what it means to be a caregiver” (p.4). Difficulty in using statistics to capture the nature of the developing
The caregiver/assessor relationship and the day to day variations in the caregiver emotional charge of caregiving were identified as study limitations (Keefe, et al.).

The CNA-D instrument (Wancata et al., 2005) is “a comprehensive research instrument to assess the needs of dementia caregivers and determine whether these needs are met” (p. 394). The negative consequences for caregivers of persons with dementia (emotional stress, financial burden, and social isolation) have prompted two decades of research aimed to reduce caregiver burden. The CNA-D consists of 18 problems areas and one optional area asking the caregiver to identify additional problems not covered in the problem areas. There are no published studies using this instrument.

**Caregiver interventions.** Several meta-analyses and relevant studies specific to dementia caregiver interventions were reviewed because problem assessment promotes intervention planning. As a point of clarification, Capezuti, Zwicker, Mezey, and Fulmer (2008) provide definitions for interventional terms. Psychoeducational interventions are structured programs that provide information about the disease process, resources and services and train caregivers to respond to behavior problems. Lectures, group discussion and written materials are led by a trained leader. Psychotherapeutic interventions usually follow a cognitive-behavioral approach and involve a therapeutic relationship between a trained professional and a caregiver. Multi-component interventions combine educational, support, psychotherapy and respite but may also include nursing management and interdisciplinary care interventions (Capezuti et al., 2008).

A meta-analysis by Sorensen, Pinquart, Habil and Duberstein (2002) reported the effectiveness of interventions for caregivers ($n = 78$) of older adults. The interventions were divided into two groups: 1) interventions that reduced the amount of care provided
(respite and increasing recipient competence) and 2) interventions that improved
caregiver well-being and coping skills. Calculations for meta-analysis were performed.
Psychoeducational, psychotherapeutic and multi-component interventions had the most
consistent effect for improving caregiver well-being but the effects were reduced for
dementia caregivers. Interventions of 7-9 sessions were thought to be adequate to
increase knowledge and ability but inadequate to reduce depression. Caregivers of
persons with dementia require more effective interventions such as respite/day care
combined with training to cope with behavior problems of the care receiver. Individual
interventions were found to be more effective in improving caregiver well-being.
Caregiver burden could be reduced but not eliminated. There were no references to
gender based interventions or gender differences. Three study limitation were identified:
1) inability to disaggregate multiple burden dimensions measured in the study, 2) many
studies with missing variable data restricted use of multivariate analysis and 3) delivery
characteristics (group or length) and intervention types were sometimes confounded
(Sorenson et al., 2002).

Another meta-analysis evaluated interventions that help caregivers cope with the
burden of caregiving (Acton & Kang, 2001). Published research studies (n = 24) that
tested 27 interventions were synthesized. Meta-analysis was used to determine
similarities and differences in studies with similar variables, to generalize and integrate
findings. Of the six interventions (support group, education, psychoeducation,
counseling, respite care and multi-component) only the multi-component interventions
significantly reduced caregiver subjective burden. The authors caution against
“blanketing subjects with a variety of services and interventions to reduce burden” (p.
Using burden as an outcome may not be the best way to evaluate intervention outcomes because of its global concept. The authors recommended research examining the positive outcomes of caregiving such as “meaning making, transcendence, well-being and life satisfaction” (p. 358) and acknowledged that burden may remain unchanged. No limitations were identified in this analysis (Acton & Kang).

A summative review of published and unpublished research reports ($n = 73$) of family caregivers of persons with dementia was completed to determine: 1) what type of family caregiver interventions have been tested and what features are important to nurses, and 2) what issues are important for researchers to address concerning caregiver intervention research (Acton & Winter, 2002). Key findings indicated that “32% of the study outcomes (burden, depression and knowledge) were improved following an intervention; furthermore, matching caregiver needs to interventional strategies is important. The limitations identified in this review of studies included: small sample sizes, lack of sampling homogeneity, lack of intervention specificity, diversity in length, duration and intensity of specific intervention strategies, poor matches between interventions and outcomes, lack of prescreening caregivers for levels of outcome variables and lack of attention to matching caregiver needs to intervention strategies (Acton & Winter).

A qualitative, descriptive study was conducted over five years in a Chicago metropolitan area to: 1) describe family caregiving issues during a 12 month period, 2) describe skill use and development and 3) identify skills needed by caregivers (Paun, Farran, Perraud, & Loukissa, 2004). Group summaries were analyzed ($n = 115$) using the ATLAS.ti program for qualitative data management to complete content analysis of the
data. Data were divided into three categories: 1) care recipient issues, 2) caregiver issues and 3) resource issues and identified that a change in knowledge alone in not sufficient to foster skill development. Caregivers reported that the learning process created a deeper sense of understanding of themselves as caregivers that gave insight into emotionally adjusting to the changes in their loved one with AD. “Caregivers’ emotional acceptance of their loved one as a new person suffering from an incurable disease distinguished the skilled from the less skilled caregiver (and) time is an essential factor in the transformation process of ongoing skill development” (Paun et al., 2004, p. 250). The lack of diversity and predominantly female population were limitations for this study.

A summative review of recent randomized controlled trials (RCT) was undertaken to identify trials that evaluated the efficacy of behavioral interventions for family caregivers seen by geriatric psychiatrists and to synthesize study findings (Schulz, Martire & Klinger, 2005). Studies on dementia caregivers (n = 41) and stroke caregivers (n = 10) met the criteria for review. The majority of the interventions tested for dementia caregivers focused on a mixture of family members and were multi-component in nature, that is, educational materials combined with some amount of counseling or skill training. Of note, fifty-one percent of the studies were not statistically powerful enough to detect small or medium effects. Overall, these studies had consistent effects in reducing caregiver depression, burden and anxiety symptoms. Some of the limitations of the studies included: 1) probably methodological flaws not remedied by RCT design, 2) the use of RCT design was not dependent on a fully implemented or fully received intervention, 3) assessment procedures in the studies were inconsistent, and 4) many studies did not assess patient outcomes.
The Schulz et al., (2005) review reported “one of the most ambitious research programs” (p. 1010) was the Resources for Enhancing Alzheimer’s Caregiver Health (REACH) trial (Wisniewski and Belle, Marcus, Burgio, Coon, Ory, Burns & Schultz, 2003) that implemented multi-component interventions across six states. The interventions included: 1) individual information and support strategies, 2) group support and family system therapy, 3) psycho-educational and skill-based training approaches, 4) home-based environmental interventions and 5) technology support systems. Each site found statistically positive results in outcomes such as burden and depression. The REACH research program reported that “interventions that actively engage the caregiver in skill acquisition aimed at regulating their own behavior result in significant improvements in caregiver depression” (Schulz et al., p. 1011).

A systematic review of RCT \( n = 44 \) examined information and support interventions for AD caregivers (Thompson et al., 2007). Data were entered into MS Excel spreadsheets. Analysis was performed using Revman version 4.2.8. Meta-analysis was undertaken for interventions that had similar focus and process. Interventions were grouped into three categories: technology based interventions (e.g. computer interventions), group-based interventions (e.g. support groups) and individual based interventions (e.g. psychoeducation). The review found no evidence that caregiver support-based and or information-based interventions were uniformly effective for all caregivers. Even though the quantitative results were inconclusive the authors suggested that at more comprehensive review of the qualitative findings may reveal meaningful results. Limiting the review to randomized trials may have limited evidence about
underlying effects of interventions available in non-random, quasi-experimental studies (Thompson et al.).

**Web-based education.** The Internet is rapidly becoming an important resource for caregiver information needs. “Information seekers declared that they use the Internet because it is fast, anonymous and always available…searching multiple sites and looking for commonality in the content (allows them to) discern the accuracy of the information” (Saba & McCormick, 2006, p. 482). Web-based interventions promoting health and emotional well-being hold promise for meeting the psychosocial and emotional needs of adult caregivers (Glueckauf, Ketterson, Loomis & Dages, 2004).

One Meta-analysis and four relevant studies focus on this topic. An Internet and telephone-based education and support network (AlzOnline) was developed, implemented and evaluated (Glueckauf et al., 2004). The study objective was to assess the impact of the program on caregiver self-efficacy, emotional growth and burden using a pretest-posttest design. Caregivers of persons with dementia ($n = 21$) were enrolled and completed the AlzOnline Positive Caregiving program. Participants were interviewed and screened to determine whether they could participate in the live Internet class or needed the toll-free telephone class. One week before beginning the 16 week classes, a staff member administered the Caregiving Self-efficacy scale, the Stress-related Growth Scale and the Caregiver Appraisal Inventory to each participant by telephone. The authors concluded that online cognitive-behavioral interventions could reduce feelings of burden and increase self-efficacy for caregiving duties. “It is possible that class participants may have grown emotionally and spiritually” during the 16 week
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intervention” (Glueckauf et al., p. 230). Limitations in this study included: small sample size, lack of control conditions and the majority of the participants were white females.

Referring again to a recent randomized quantitative telephone interview study (NAC/AARP, 2009), caregivers \( n = 1480 \) and caregivers of persons 50 years and older \( n = 288 \) were surveyed concerning 22 aspects of caregiving. The demand for caregiver information needs has increased during the last five years. Two aspects of this study were of particular relevance: 1) sources used for caregiving information, and 2) use of technology in caregiving. Fifty-three percent of all caregivers reported they used the Internet in the past year to retrieve caregiving information about their loved one’s condition or treatment (78%), caregiving services (53%), finding healthcare professionals (36%), information about care facilities (34%) and caregiving tasks (26%). The study concluded that “technology offers great promise for facilitating some of the responsibilities that caregivers’ shoulder and more generally to improve the care of their recipients” but did not cite study limitations (NAC/AARP, 2009, p. 25).

A meta-analysis was conducted to compare patient/client (female = 5,841; male = 5,729) knowledge and behavior change between web-based interventions and non-web-based interventions (Wantland, Portillo, Holzemer, Slaughter & McGhee, 2004). The focus of the educational content was self-care in chronic disease. The positive outcomes included: “increased exercise, increased knowledge of nutritional status, increased knowledge of asthma treatment, increased participation in healthcare, slower health decline, improved body shape perception and 18-month weight loss maintenance” (p. 2). Individually tailored materials resulted in longer web-site sessions and more visits. Sites with chat rooms demonstrated increased social support. Selection bias was a possibility
if “web-savvy” participants and researchers were more likely to participate in web-based interventions than non-“web-savvy” persons (Wantland et al., 2004, p. 11).

A worksite Internet multimedia program for family dementia caregivers ($n = 299$) was evaluated for efficacy in this randomized control trial (Beauchamp et al., 2005). The validated instruments used to collect data for analysis included the: CES-D, State-trait Anxiety inventory, Caregiver Strain scale, Positive Aspects of Caregiving and a satisfaction survey. Data were analyzed using multivariate analysis and dose-response analysis. The intervention involved a treatment and a control group. The treatment group received access to the multimedia intervention Caregiver’s Friend: Dealing with Dementia that included text materials and videos that model positive caregiver strategies. The control group did not have access for 30 days. The treatment group demonstrated significant improvement in depression, anxiety, level and frequency of stress, caregiver strain, self-efficacy, intention to seek help and positive perceptions of caregiving. Additional email contact may have had some influence on participant expectation and attention received in the treatment group. The researchers concluded that Internet intervention delivery is a cost effective, efficient, convenient strategy for delivering individualized educational information and skill training (Beauchamp et al., 2005).

A recent internet-based survey was developed to explore caregivers of persons with Lewy Body Dementia experiences, needs and burden (Galvin, Duda, Kaufer, Lippa, Taylor & Zarit, 2010). SPSS software was used to analyze data. Survey responses ($n = 971$) indicated a lack of service utilization even in crisis situations and preferences for web-based information (76% of respondents). The majority of the caregivers were women (spouses and daughters). Several study limitations were identified: respondents
were self-reported caregivers, participants were highly educated and not representative of the dementia caregiver population and survey questions were investigator generated (Galvin et al., 2010).
Appraisal and Synthesis of Evidence

This evidence-based practice project to develop targeted, gender specific WBEMs is based on caregivers’ of persons with AD key problems identified during two major phases: 1) review of research literature and 2) a planned AD caregiver assessment of problems/needs using a web-based format of the CNA-D instrument (Gies, Pierce, Steiner, van der Bijl & Salvador, 2010; Wancata et al., 2005). The following section appraises and synthesizes the research literature in five areas: 1) caregiver problems/needs, 2) caregiver gender differences, 3) caregiver assessment, 4) caregiver interventions and 5) web-based education.

Phase I: Research Literature (Appendix A)

Caregiver problems/needs. Four studies identified major caregiver needs/problems. In general, caregivers rated information needs a higher priority than support needs (Wackerbarth & Johnson, 2002). Many caregivers of persons with dementia are interested in finding information on care services (home care, assisted living and nursing home placement) and legal and financial planning (NAC/AARP, 2009; Edelman et al., 2006; Wackerbarth & Johnson). There was high interest in information about behavior care management and easy activities for care recipients (NAC/AARP, 2009; Nichols et al., 2006). Caregiver information needs tend to escalate as the care recipient’s dementia stage progresses (Nichols et al.,). Finding personal time and emotional support along with emotional stress were concerns for many caregivers (NAC/AARP; Nichols et al.,; Wackerbarth & Johnson) especially in the later stages of dementia. Dealing with family and friends, genetic aspects of AD and alternative medicine or treatment for memory loss were other reported information needs (Edelman et al., 2006). Female caregivers
identified a need for interaction and support from others (Wackerbarth & Johnson) while men identified higher interest in healthy lifestyle information and help with care recipient eating problems (Nichols et al.).

**Caregiver gender differences.** Fourteen studies were reviewed pertaining to gender differences in problems/needs for caregivers. The research literature revealed some evidence of gender based differences in caregivers of persons with dementia. Men and women differ in the way they are affected by the experience of caregiving and how they approach caregiving. Women report more burden, anxiety and depression (Bedard et al., 2005; Garity, 1997; Luchetti et al., 2009; Navaeie-Waliser et al., 2002; Papastavrou et al., 2009; Pinquart & Sorensen, 2006; Thompson et al, 2004). Women identify with the caregiving role while men view caregiving as a task to complete (Thompson et al, 2004). Women are more likely to day dream or use denial as a coping mechanism and they are less likely to use support services (Sugiura et al., 2009; Sun et al., 2008). Men, on the other hand, are 1) more resistant to stress and tend to adapt to change by blocking or psychologically distancing themselves from the care receiver, 2) exert more force and 3) tend to focus on tasks (Calasanti & King, 2007; Thompson et al.,). Men are more likely to use support services as they have difficulty assisting with activities of daily living and have difficulty adjusting to loss of personal time (Ford et al., 1997; Papastavrou et al., 2009).

**Caregiver assessment.** Although caregiver assessment is viewed as important by many healthcare professionals (Czaja et al., 2009; FCA, 2006; Feinberg et al., 2006; Guberman et al., 2001, Guberman et al., 2007; Keefe et al., 2008; Wancata et al., 2005) a review of the literature reveals a paucity of caregiver assessment research studies. Only
three caregiver assessment research studies were identified for review and each
assessment instrument was different; that is, there was neither national nor international
standardization of what domains are included in assessment instrumentation (see
Appendix B). The C.A.R.E. Tool (Guberman et al., 2001) is an assessment instrument
for all types of caregivers. Only one assessment instrument, the CNA-D, has been
developed specific to caregivers of persons with dementia (Wancata et al.,) but there are
no published studies using this instrument. The recently developed Risk Appraisal
Measure (RAM) is a brief screening measure for caregivers of persons with dementia that
shows promises for use in research, clinical and community settings (Czaja et al.,).

Caregiver interventions. There is a need for effective caregiver interventions to
support caregivers of persons with dementia in their delivery of care. Six studies were
discussed describing successful caregiver intervention strategies. Multi-component
interventions are found to be the most effective strategy for supporting both men and
women. Respite/day care combined with training to cope with behavior problems of the
care receiver and individual interventions were found to be more effective in improving
caregiver well-being; support group, education, psychoeducation, and counseling were
helpful (Acton & Kang, 2001; Sorenson et al., 2002). Matching caregiver needs to the
care recipient’s AD stage and applying a caregivers’ learning process can create a deeper
sense of self for the caregiver as they transition for novice to skilled caregiver (Acton &
Winter, 2002; Paun et al., 2005 Schulz et al., 2005). Technology based interventions (e.g.
computer interventions), group-based interventions (e.g. support groups) and individual
based interventions (e.g. psychoeducational) need to be analyzed for qualitative
significance. There is not enough evidence to make any definitive conclusions about any
one intervention. Each has relevance in assisting caregivers of persons with AD unique needs. Recent caregiver surveys find caregivers want information and are using web-based technology as a significant resource (NAC/AARP, 2009).

**Web-based education.** Education is one intervention that can be used to improve the quality of life for caregivers of persons with dementia. There is also evidence that caregivers use the Internet to find information for needs and problems (Galvin et al., 2010; NAC/AARP, 2009) and the literature supports development of web-based interventions and focused interventions to respond to the unique needs of both men and women dementia caregivers (Wantland et al., 2004). Some interventions for these groups have been more successful than others. The difficulty is that each individual, whether male or female, has unique caregiver challenges and uses different coping and problem solving strategies. As web-based technology advances, there is great potential for health care providers to be able to deliver interactive and face-to-face interventions via the Internet in the future (Glueckauf et al., 2004).

The Pew Internet and American Life project (2010) reported that 79% of American adults use the Internet. The fastest growing subgroup of Web users are the baby boomers born between 1946-1965 and persons born before 1946 (Chaffin & Maddux, 2007). Cost may be prohibitive for some, and not all caregivers are computer savvy. Libraries, schools and agencies such as the Area Office on Aging provide public access for computer use. Web-based education and support is available and a viable option for most American caregivers.

Finally, applying principles of adult learning and instructional design are important considerations in the development of WBEMs for AD caregivers. Adults learn
best when they: 1) know the practical reason for what they are asked to learn, 2) can use previous experiences as a foundation for new learning, 3) can take responsibility for making decisions about the learning, 4) see the relevance of learning to their life patterns, 5) use problem-based learning rather than memorization and 6) are internally motivated to learn (Stern & Kaur, 2010). This is an andragogical rather than a pedagogical approach. Additionally, instructional design principles provide structure for developing programs that are responsive to the adult learner. “Instructional design systematically studies how learning is improved by following the ADDIE cycle of analysis, design, development, implementation and evaluation” (p. 72). Using these principles, learning is theory based, matches the learner’s goals and is delivered in a systematic, effective, accessible and reflective format (Stern & Kaur).

**Conclusion**

Adult caregivers of persons with AD experience problems/needs associated with long term caregiving responsibilities. Finding information about care services, legal and financial planning, behavior care management and stress and coping are key issues. Gender differences are identified in the literature. Although the majority of AD caregivers are women, men are equally vulnerable to the consequences of long term caregiving. Women and men seem to have different coping mechanisms. Women tend to experience more stress, burden and health issues but are reluctant to seek services; whereas, men struggle with skills related to care recipient personal care, are distressed over loss of personal time and are more likely to use support services. Assessment can identify caregiver problems/needs and direct healthcare professionals toward interventional strategies that support caregiver health and well-being. Caregivers of
persons with AD rate information needs higher than support service needs. Many seek information from the Internet. Delivering educational information based on the principles of adult learning and instructional design via the Internet may prove to be a cost effective, efficient way to restore congruence and improve caregiver quality of life.

**Phase II: Planned AD Caregivers’ Assessment of Problems/Needs**

The purpose of this Doctor of Nursing Practice (DNP) project is to assess caregivers for gender differences in key problems reported by caregivers caring for persons with AD and to develop targeted gender specific web-based education materials to address these problems/needs. Web-based educational support will facilitate/change access to information for caregivers of persons with dementia. Once caregiver problems/needs are clarified, interventions can be designed to address them. Recent research on caregivers and caregivers of persons with dementia identifies some gender based differences in caregiving problems and needs.

Family members provide the majority of care for persons with dementia, and are essential resources not only for care recipients, but also for the healthcare system. Understanding the problems and needs of family caregivers of persons with dementia is a vital component in managing the consequences of long term caregiving. Caregiver assessment is the first step in determining needs and resources and in promoting caregiver sustainability through evidence-based interventions. Caregiver assessment can identify areas of needed support and provide the basis for planning interventions to assist care work. A small, planned AD caregivers’ assessment of problems/needs seeks to understand what these problems in caring are and whether male and female problems/needs differ.
A funded study made possible by a research grant from the Rehabilitation Nurses Foundation (RNF) recently examined the experience of using the comprehensive CNA-D assessment instrument (Wancata, et al., 2005) to assess the problems of dementia caregivers in the original face-to-face interview format versus a new self-administered web-based format. The title of the pilot study is *Web-based Psychosocial Assessment for Caregivers of Persons with Dementia: A Feasibility Study* (Gies et al., 2010). This EBP DNP project was expanded to enable the author to use the CNA-D web-based version (see Appendix C) to assess AD caregivers and identify gender differences in problems/needs.

**Evidence-based practice assessment goals.** There are two goals related to assessing the problems/needs of caregivers of persons with AD: 1) to identify key problems in caring for persons with AD using the web-based CNA-D instrument and 2) to determine if there are gender differences in key caregiving problems/needs for caregivers of persons with dementia within a small cohort of caregivers in northern Ohio.

**Human subject protection IRB approval.** Approval to conduct the funded study and this EBP project was obtained from the University of Toledo Institutional Review Board (IRB) (see Appendix D). Data were gathered from participants from the University’s Geriatric Center, a local caregiver conference and the Northwest Ohio Chapter of the Alzheimer’s Association. All participants were assured in writing that the information they provided was confidential, no individual data was be reported and services were not affected by their decision to participate in the study. Other than mild anxiety, no other risks to the participants were anticipated during the study. All information and data will be kept in a locked file cabinet in the locked office of the
research investigator. The information and data will be securely stored for six years by the primary investigator and then destroyed.

**Methods.** This EBP project determined the feasibility of using the web-based version of the CNA-D assessment instrument to determine gender-based caregiver problems/needs and develop education modules to meet the identified needs. After completing the informed consent (see Appendix E) each participant was asked to complete the web-based adaptation of the *Carers’ Needs Assessment for Dementia* (CNA-D) instrument (Wancata et al., 2005). Ten caregiver participants were to be recruited (female = 5; male = 5) to complete the web-based assessment.

**CNA-D instrument.** The CNA-D instrument is a comprehensive, research instrument recently adapted for use in a web-based format. Although there are instruments that assess the problems of persons with dementia, the CNA-D is the first instrument designed to assess the problems of the caregivers of persons with dementia (Wancata et al., 2005). The instrument assesses 19 problem areas.

The first nine problem areas include: lack of information about dementia, lack of information about treatment, lack of information about services, financial burden, legal issues, disappointment caused by illness (concerns about the future), communication or conflict problems with the patient, burdened by patient behavioral problems and problems causes by crises. The last nine problem areas include: not enough time for oneself, social isolation (inter-family conflicts), burden caused by dangerous situations, fear of stigmatization and discrimination, feelings of guilt/blame, missing nursing skills, difficulties with household tasks, burned out/overstrained by care and physical or psychiatric illness of the care recipient (Wancata et al., 2005). The final part of the
assessment asks the caregiver to list any “other problems” they are experiencing and then identify their three key problems or needs.

The CNA-D instrument was determined to be a “valid and reliable instrument for comprehensively assessing the needs of dementia caregivers” in Austria (Wancata et al., 2005, p. 393). Inter-rater and test-retest reliability was tested and confirmed among dementia caregivers \((n = 45)\). Content validity was performed and confirmed in a separate survey of caregivers \((n = 40)\) and professionals \((n = 40)\). Significant positive association was found between the CNA-D problems and unmet needs and the Zarit Burden Inventory total score (Wancata et al.).

**Results.** The results of caregiver assessment are discussed in Part II.
Practice Plan Change

As front line healthcare providers, DNP practitioners should be involved in efforts to respond to the consequences of caregiving in primary care and community settings through translation of research into practice and practice improvement measures evaluation. Innovative, targeted, population focused web-based intervention modules could be an effective, convenient caregiver support mechanism. By identifying gender differences in the review of the research literature and in caregiver assessment, this evidence-based practice project could add to gender based caregiver intervention literature and research. Under the direction of the DNP project committee, at least 4 gender specific modules (two for females and two for males) will be developed by the author and evaluated for utility and functionality by a small group of male \((n=3)\) and female \((n=3)\) volunteer caregivers of persons with Alzheimer’s disease.

Project Process

Web-based material guidelines. The Health on the Net Foundation (HON) (Saba & McCormick, 2006) compiled a set of guidelines for developing health information for web-based materials that will be used to evaluate content credibility for the education modules. The HON principles are: authority (qualifications of the author), complementary (information supports health care provider patient relationship), confidentiality (respect for privacy of personal information), attribution (sources and dates of public information are cited), justifiability (back up for claims of benefits and performance), transparency (accurate email contact), financial disclosure (funding agencies) and advertising and editorial policy (Saba & McCormick).
**Education module development.** Evidence from the literature review and the CNA-D caregivers’ assessment of problems/needs will be combined to determine the key problems/needs of men and women caregivers of persons with dementia and to develop the content for targeted WBEMs. The design of each educational module will be tailored to the subject matter with emphasis on simplicity and visual interest. Module content will follow the same format to maintain consistency and balance.

The basic format will consist of an introduction of the topic, topic educational information, points to consider, web links and/or short video clips to maintain interest and a summary of important points to remember. Pierce (2010) recommends general considerations for developing written education materials: 1) key concepts should flow from goals, 2) begin each paragraph with a clear topic sentence, 3) add Internet resources to stimulate interest, 4) arrange content in a logical manner, and 5) use accurate, reputable resources for information. The language and style should reflect sensitivity to culture and gender, a glossary is helpful to clarify complex wording and the content should be at a sixth grade reading level. Pictures and captions can be used to enhance learning and retain important information (Pierce). Learning styles can be considered even though this may be difficult to address in a web-based format.

Design guidelines for active-learning web-based templates suggested by Lohr and Ku (2003) include: 1) designing templates around questions the learner may have such as “where do I start?”, 2) avoiding metaphors (they detract from the content), 3) using multiple visual “chunking” strategies such as “graphics, white space, headings, typography, and short...Web pages” (p. 224), and limiting the number of links outside of the main menu. Clearly organizing instructions and access, offering materials that
motivate the learner and ensuring that the learner moves toward clear learning objectives are additional recommendations.

Garity (1997) conducted a learning style study in AD family caregivers (n = 76) enrolled in Alzheimer’s Association support groups in Eastern Massachusetts. Study instruments included the: Burden interview, Original Learning Style Inventory, Resilience Scale, and Ways of Coping. The authors described four types of learners: 1) accommodator (concrete experience and active involvement), 2) diverger (concrete experience and reflective observation), 3) assimilator (inductive reasoning and theoretical principles) and 4) converger (problem-solver, decision maker, practical application of ideas). The study found that the majority of women (62%) were divergers while men were predominantly divergers (42%) and assimilators (35%). This information could be helpful when interventions involve group work (Garity).

Usability factors for web-based programs recommended by the National Institute on Aging and the National Library of Medicine were summarized by Chaffin and Maddux (2007). The usability factors are: limited animation use to avoid screen clutter, simple language, definitions for difficult words, plain typeface with 12-14 font, double spacing, contrast between text and background, use of upper and lower case lettering, yellow/blue/green colors are prohibited in close proximity to each other, simple page to page navigation, large buttons and pictures, single mouse click for information and a tutorial for website use.
Planned Evaluation

Targeted Educational Web-based Modules

Following module development, a small convenience sample of an equal number of male (n=3) and female (n=3) caregiver volunteers will be recruited to evaluate clarity, functionality and utility of the WBEMs content via a written caregiver questionnaire. The Caregiver Evaluation Questionnaire (see Appendix J) was submitted to and approved by the UT IRB. Demographic information of the caregiver volunteers will be reviewed. The questionnaire responses will be reviewed, described and summarized. Additional comments from the volunteers will be thoughtfully considered for revisions and or additions to the educational modules.

Evidence-Based Project Evaluation

The project will be evaluated for utility and functionality for future use on the Internet via caregiver evaluation. Web-based education interventions have been found to be cost effective, efficient and effective learning opportunities (Beauchamp et al., 2005). There are multiple interventional strategies to support caregivers identified in the literature. Education is one proven strategy that can be used to improve the quality of life for caregivers of persons with AD and will be the only strategy used in this project. These modules could be combined with other interventional strategies to form a multi-component intervention. Primary care providers may find this type of web-based education a useful caregiver resource in the future as more primary care offices convert to electronic medical records and expand the use of computer technology in the clinical setting.
Project Considerations

No funding was requested for developing and evaluating the gender specific WBEMs. The technology expertise of The University of Toledo (UT), College of Nursing and the UT Distance Learning department will be used to develop and produce a “mock-up” template and create presentations on a system known as ECHO 360. The ECHO 360 is a web-based system designed to capture and publish lectures on line for a viewing audience (UT, College of Health Science and Human Service, 2010). The audio and video capabilities of this system mimic a one way face-to-face encounter. The recordings allow audience participants to review material multiple times and access information at times that are most convenient for the learner. The educational modules will have accompanying written handouts.
Planned Data Analysis

Literature Review

Eight U.S. studies and one Canadian study best represent gender differences in problems identified in the literature. Three of the nine studies (33%) identified depression/illness, two studies (22%) identified communication and two studies (22%) identified time for self as key concerns for female caregivers. One of the nine studies identified two key concerns for male caregivers, time for self (11%) and lack of nursing skills (11%) and a second study identified care is a burden (11%) and critical situations (11%) as key concerns.

The level of evidence (LOE) for these studies ranged from Level 1 (strongest level – systematic review) to Level IV (less strong – non-experimental studies) on a Level I through Level VI scale (Levin et al., 2008). The level of evidence and key problems/needs identified in these studies are correlated by gender with the questions in the CNA-D assessment instrument as shown in Table 2.
<table>
<thead>
<tr>
<th>Literature Review (LOE)</th>
<th>Problems</th>
<th>Information needs</th>
<th>Group</th>
<th>Corresponding CNA-D Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nichols et al. (2005)</td>
<td>Healthy lifestyle, Feeding Care recipient</td>
<td>Male caregivers (AD)</td>
<td>#10 time for self</td>
<td></td>
</tr>
<tr>
<td>LOE = II</td>
<td></td>
<td></td>
<td>#13 lack of skill</td>
<td></td>
</tr>
<tr>
<td>Calasanti &amp; King. (2007)</td>
<td>Deal with negative feelings by: Focus on tasks, block emotions, minimize disruption, distraction, self-medication</td>
<td>Male caregivers (AD)</td>
<td>#17 care is burden/strain</td>
<td></td>
</tr>
<tr>
<td>LOE = *IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ford et al., (1997)</td>
<td>Dealing with dangerous behavior and agitation</td>
<td>Male and Female caregivers (AD)</td>
<td>#9 critical situation</td>
<td></td>
</tr>
<tr>
<td>LOE = IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wackerbarth &amp; Johnston, (2001)</td>
<td>Finding support for self</td>
<td>Female caregivers (AD)</td>
<td>#10 time for self</td>
<td></td>
</tr>
<tr>
<td>LOE = IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bedard et al., (2005)</td>
<td>Role burden with problem behavior ADL, repetition</td>
<td>Female caregivers (AD)</td>
<td>#8 behavior</td>
<td></td>
</tr>
<tr>
<td>LOE = IV</td>
<td></td>
<td></td>
<td>#7 communication</td>
<td></td>
</tr>
<tr>
<td>Calasanti &amp; King. (2007)</td>
<td>Wives reluctant to diminish care receiver's (husband's) authority; reluctant to coerce or &quot;swallow empathy&quot;</td>
<td>Female caregivers (AD)</td>
<td>#7 communication</td>
<td></td>
</tr>
<tr>
<td>LOE = *IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Garity, (1997)</td>
<td>Burden and personal strain</td>
<td>Female caregivers (AD)</td>
<td>#18 depression /illness</td>
<td></td>
</tr>
<tr>
<td>LOE = IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thompson et al., (2004)</td>
<td>Females experienced more physical manifestations of stress than men</td>
<td>Female caregivers (AD)</td>
<td>#18 depression /illness</td>
<td></td>
</tr>
<tr>
<td>LOE = IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Navarre-Walser et al., (2002)</td>
<td>Women under more stress to provide greater volume of care with less formal support</td>
<td>Female caregivers in general</td>
<td>#3 services</td>
<td></td>
</tr>
<tr>
<td>LOE = IV</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pinquart &amp; Sorenson, (2006)</td>
<td>Women have higher levels of burden and depression, lower levels of sense of well-being and physical health</td>
<td>Female caregivers in general</td>
<td>#17 care is burden/strain</td>
<td></td>
</tr>
<tr>
<td>LOE = I</td>
<td></td>
<td></td>
<td>#18 depression /illness</td>
<td></td>
</tr>
<tr>
<td>Women have lower levels of social resources</td>
<td>Increase support decrease stress</td>
<td>Female caregivers in general</td>
<td>#10 time for self</td>
<td></td>
</tr>
<tr>
<td>Women are less likely to institutionalize care recipient</td>
<td></td>
<td>Female caregivers in general</td>
<td>#13 ashamed, worry about ECF</td>
<td></td>
</tr>
</tbody>
</table>
Caregiver CNA-D Assessment

The CNA-D assessment data is descriptive. Responses of the participants will be described and statistical analysis will be limited to frequency distributions and measures of central tendency (mean, median and mode). The variables between male and female groups will be reviewed and described. Different age groups and data collected at a single point in time comprise this descriptive, comparative design project.

The Evidence-based Practice Project

Four educational modules (two male and two female) will be developed and focus on key gender specific problems/needs identified by combining the responses from the CNA-D assessment and the literature review. The modules developed for males will be evaluated by male caregivers and the modules developed for females will be evaluated by female caregivers. Both male and female group evaluators will use the author developed Caregiver Evaluation Questionnaire to evaluate the educational modules. Data from the questionnaires will be reviewed and descriptive statistics used to report outcomes. All data from the CNA-D assessments, the literature review, and the Caregiver Evaluation Questionnaire responses will be analyzed, described, discussed and summarized in Part II: The Evidence-based Practice Project. The project outcomes will be related to the Framework of Systemic Organization (Freidemann, 1995; 2010). Final discussion will consider whether targeted gender specific WBEMs have potential to enhance caregiver support and how doctoral prepared nurse practitioners can use this technology in primary care settings and in the community in the future.
Part II: The Evidence-based Practice Project

Project Implementation

Guided by the Framework of Systemic Organization (Friedemann, 1995, 2010) to promote a more congruent, supportive environment for caregivers, this EBP project was divided into Part I (project proposal) and Part II (project implementation and evaluation). The five phases of the Stetler Model were applied to organize the project activities as seen in Table 1. In Part I, during preparation (phase 1) and validation (phase 2), gender differences in reported problems of caregivers of persons with AD were identified in the literature.

In this section, Part II, caregiver assessment results are compared to the review of the literature, key male and key female problems are identified (phase 3 comparative evaluation/decision making) and gender specific modules are developed (phase 4 translation/application). Finally, the WBEMs are evaluated by a second group of male and female caregiver volunteers and project findings and conclusions are summarized and disseminated (phase 5 evaluation).

Population of Interest and Practice Setting

Caregivers of persons with AD are the population of interest for this project. Persons with AD require progressively more complex care over a long period of time (Thompson et al., 2007). Their caregivers are most often unpaid family members who require support to manage their care responsibilities (Alzheimer’s Association, 2010). The healthcare system depends on these caregivers to be the eyes, voice and hands of persons with AD. As leaders in healthcare, nurse practitioners are prepared to assess caregivers in the clinical setting, identify caregiver problems and design innovative
approaches to help caregivers cope with the demands of caregiving in order to maintain personal health and provide competent home care.

A review of the literature found gender differences in how men and women approach and are affected by the experience of caregiving. In an effort to identify gender differences in caregiver problems/needs in clinical and community settings, male and female caregivers were assessed using a web-based adaptation of the CNA-D instrument (Wancata et al., 2005). Ten caregivers were recruited from a geriatric practice, a caregiver conference, and a local Alzheimer Association chapter in northwest Ohio and enrolled for web-based assessment following IRB approval. Originally, it was proposed that five male and five female caregivers would be recruited to complete the CNA-D assessment; however, availability, computer access, and lack of computer skills limited the convenience sample to four male and six female participants. The participants were predominantly White non-Hispanic, 33-75 years of age, with 16 years of education, in good health, caring for spouses or mothers as seen in see Table 3.
Table 3

*CNA-D Caregiver Assessment: Participant Demographics (n=10)*

<table>
<thead>
<tr>
<th></th>
<th>Male Caregivers (n = 4)</th>
<th>Female Caregivers (n = 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (range)</td>
<td>54-75 years</td>
<td>33-63 years</td>
</tr>
<tr>
<td>Education (mean)</td>
<td>16.0 years</td>
<td>15.5 years</td>
</tr>
<tr>
<td>Ethnic background</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black non Hispanic</td>
<td>0 (00.0%)</td>
<td>1 (16.6%)</td>
</tr>
<tr>
<td>White non Hispanic</td>
<td>4 (100 %)</td>
<td>5 (83.3%)</td>
</tr>
<tr>
<td>American Indian or Alaska Native</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Asian or Pacific Island</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>General health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Fair</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Good</td>
<td>2 (50.0%)</td>
<td>5 (83.3%)</td>
</tr>
<tr>
<td>Very good</td>
<td>1 (25.0%)</td>
<td>1 (16.6%)</td>
</tr>
<tr>
<td>Excellent</td>
<td>1 (25.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Care recipient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>2 (50.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Mother</td>
<td>1 (25.0%)</td>
<td>5 (83.3%)</td>
</tr>
<tr>
<td>Father</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (25.0%)</td>
<td>1 (16.6%)</td>
</tr>
</tbody>
</table>

Data from the caregiver assessment were reviewed and matched to the corresponding CNA-D problem number as seen in Table 4. The female caregiver participants selected problem numbers 1, 3, 4, 8, 11, 15, 16, and 17 one time each (16.6%); problem numbers 6, 10, 12, and 14 were selected two times each (33.3%) and problem number 7 three times (50%). Male caregiver participants selected problem numbers 1, 2, 3, 7, 10, and 13 one time each (25%) and problem numbers 4, 11, and 17 two times each (50%).
In preparation for gender specific WBEM development, module topics were planned based on key male and female problems/needs. Key problems were ranked based on: 1) the number of times (percent score) a problem/need was identified in the literature (n=9) or in assessment (male=4; female=6) and 2) problems identified both in the literature and in the caregiver assessment groups were ranked higher than problems.
identified in only the literature or only in the assessment groups. Problems/needs with higher percent scores and with both literature and assessment support were considered for module development before problems/needs with high percent scores only.

For females, the two key problem topics were selected based on percent scores and literature and assessment support were: 1) *communication* (literature 22% and assessment 50%) and 2) *time for self* (literature 22% and assessment 33.3%). For males, the first topic, *care is a burden/strain* was selected based on percent scores and literature (11%) and assessment (50%) support. Two problems/needs were considered for the second male topic based on percent scores and assessment support only (50%). The *financial concerns* topic was chosen over *seeing others less/family tension* based on: 1) the availability of a financial expert, 2) student preference and 3) DNP project committee consensus. With the two male and the two female topics identified, steps to consider personnel and financial resources and develop the educational module template could proceed. The literature findings and the CNA-D assessment findings are compared in Table 5.
<table>
<thead>
<tr>
<th>CNA-D Problem Areas</th>
<th>Assessment Female caregivers (n = 6)</th>
<th>Literature Review Female caregivers (n = 9 studies)</th>
<th>Assessment Male caregivers (n = 4)</th>
<th>Literature Review Male caregivers (n = 9 studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1 Info illness</td>
<td>1 (16.6%)</td>
<td>1 (11%)</td>
<td>1 (25%)</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>#2 Info Treatment</td>
<td>1 (16.6%)</td>
<td>1 (11%)</td>
<td>1 (25%)</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>#3 Services</td>
<td>1 (16.6%)</td>
<td>1 (11%)</td>
<td>1 (25%)</td>
<td>1 (25%)</td>
</tr>
<tr>
<td>#4 Financial Concerns</td>
<td>1 (16.6%)</td>
<td></td>
<td>2 (50%)</td>
<td></td>
</tr>
<tr>
<td>#5 Legal Concerns</td>
<td>2 (33.3%)</td>
<td></td>
<td>1 (25%)</td>
<td></td>
</tr>
<tr>
<td>#6 Sadness Worry</td>
<td>3 (50%)</td>
<td>2 (22%)</td>
<td>1 (25%)</td>
<td>1 (11%)</td>
</tr>
<tr>
<td>#7 Communication</td>
<td>1 (16.6%)</td>
<td></td>
<td>1 (25%)</td>
<td></td>
</tr>
<tr>
<td>#8 Behavior</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
<td>1 (11%)</td>
</tr>
<tr>
<td>#9 Critical Situation in last three months</td>
<td>1 (11%)</td>
<td></td>
<td>1 (25%)</td>
<td></td>
</tr>
<tr>
<td>#10 Time for Self</td>
<td>2 (33.3%)</td>
<td>2 (22%)</td>
<td>1 (25%)</td>
<td>1 (11%)</td>
</tr>
<tr>
<td>#11 See Others</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less/Family Tension</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#12 Fear Danger for Patient</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#13 Afraid Ashamed/Worry about quality ECF</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#14 Guilt</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#15 Lack Nursing Care Skills</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#16 Not Enough Time for Chores</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>#17 Care is a burden/strain</td>
<td>1 (16.6%)</td>
<td>1 (11%)</td>
<td>2 (50%)</td>
<td>1 (11%)</td>
</tr>
<tr>
<td>#18 Depression or Physical Illness</td>
<td>3 (33%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Key Female Problems**
- Communication (#7)
- Time for self (#10)

**Key Male Problems**
- Financial concerns (#4)
- Care is burden/strain (#17)
Identification of Resources: Personnel

This project required information technology expertise beyond the scope of the author; therefore, the University instructional designer (ID) from the Distance Learning department and the technology director from the College of Nursing were invited and accepted the opportunity to be key project members. The ID agreed to collaborate with the author to create the educational module template and upload content for each module segment. The technology director agreed to provide computer equipment and ECHO 360 scheduling, training and support.

Several other professionals were included as essential team members. A certified financial planner with nursing and eldercare advocate experience was invited and agreed to tape a module segment for men on financial concerns related to caregiving. A masters prepared social worker and facilitator for the men’s support group at the local Alzheimer’s Association was invited and agreed to tape a module segment on male caregiver burden and strain. The Alzheimer’s association chapter director, the men’s support group facilitator and the author collaborated to identify caregiver volunteers who would be willing to evaluate the WBEMs once the modules were developed. The support of the University professionals and the Alzheimer Association administration and staff was fundamental to the development success of this EBP project. The author, a certified nurse practitioner with geriatric and caregiver expertise, assumed responsibility for developing the content outlines for the two male and the two female modules and for taping the female module segments on time for self and communication.

Availability, time and inexperience using the ECHO 360 technology were the only limitations identified for some of the team members.
Identification of Resources: Financial

No funding was requested for developing and evaluating the WBEMs. The technology director, the instructional designer, the financial expert and the social worker generously donated resources and services at no cost; however, projected cost for these resources and services is estimated in Table 6 based on current market service charges.

Table 6

_Evidence-Based Project Projected Cost_

<table>
<thead>
<tr>
<th>EBP Project Resources</th>
<th>Service Hours</th>
<th>Cost per hour</th>
<th>Projected Cost</th>
<th>Incurred cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instructional designer</td>
<td>20</td>
<td>$100</td>
<td>$2000</td>
<td>$0.0</td>
</tr>
<tr>
<td>Technology Director</td>
<td>10</td>
<td>$100</td>
<td>$1000</td>
<td>$0.0</td>
</tr>
<tr>
<td>Financial expert (CFP)*</td>
<td>1</td>
<td>$100</td>
<td>$100</td>
<td>$0.0</td>
</tr>
<tr>
<td>Counselor (MSW, LISW)*</td>
<td>1</td>
<td>$100</td>
<td>$100</td>
<td>$0.0</td>
</tr>
<tr>
<td>Nurse Practitioner</td>
<td>180</td>
<td>$50</td>
<td>$9000</td>
<td>$0.0</td>
</tr>
<tr>
<td>ECHO 360 rental</td>
<td>4</td>
<td>$250 hour #1</td>
<td>$850</td>
<td>$0.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>$200 / hour</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>216</td>
<td></td>
<td>$13,050</td>
<td>$0.0</td>
</tr>
</tbody>
</table>

*Honorarium

The projected cost of developing the four original WBEMs for this EBP project is $13,050. Based on the projected cost, the cost per module is estimated at $3262. New educational modules on different topics could be developed at a lower cost as the projected cost of the original modules includes template development. Future expenditures to consider include the development of an introductory web page, module maintenance, module updating and possibly marketing. There is no cost anticipated for caregivers of persons with AD to access the WBEMs but depending upon whether private or public computer access is used, there could be a cost associated with computer use or printing materials.
Ethical and Legal Considerations

IRB approval was received for a web-based version of the CNA-D instrument (see Appendix D). Each caregiver was advised of the study purpose and completed a consent form prior to participation (see Appendix E). The IRB approved the Caregiver Evaluation Questionnaire but did not require consent forms for the caregiver volunteers who evaluated the web-based modules. Volunteer consent is implied upon return of each questionnaire. All IRB protocols were followed and confidentiality of the participants was maintained. There were no other ethical or legal considerations associated with this project.

Process for Implementation

Supporting rationale for implementation of this EBP project can be found in the nursing standard of practice protocol goal for family caregiving to “identify variable strategies to monitor and support family caregivers” (Capezuti et al., 2008, p. 149). These strategies include: 1) identifying caregiving issues, 2) assisting caregivers in finding and using resources, 3) helping caregivers manage responses to caregiving and 4) using interdisciplinary approaches. Each of these strategies was integrated into this EBP project. Once the personnel, technology and financial resources were identified and secured, project implementation was conducted in five steps during a period of three months.

Step 1. As originally proposed, the template design for the WBEMs consisted of four sections: 1) introduction, 2) learning objectives and presentation, 3) relevant web links and materials for printing and 4) references. Designing the template required frequent, repeated dialogue with and direction from the instructional designer concerning
colors, format, style, audience analysis, interface usability, sequencing, validating website credibility and proof reading following the ADDIE cycle of analysis, design, development, implementation and evaluation (Stern & Kaur, 2010). Meetings and discussions were conducted face-to-face, by email and by telephone. To insure ease-of-use for caregivers, all four modules were designed to be accessed on one page with one mouse click. Learning objectives and introduction drafts were prepared for each topic: financial concerns and caregiver burden/strain for the men and communication and time for self for the women. Meetings with the two male topic experts were scheduled to plan content and EHCO 360 taping sessions.

**Step 2.** The introduction and the content outlines were prepared for the male and female WBEMs based on current literature, guidelines and protocols for caregiver support. Introductions for each WBEM scored reading levels ranging from 6th to 10th grade reading levels. The content outlines for the male modules were emailed to and reviewed with the finance expert and the social worker. A PowerPoint presentation was produced by the author for the burden/strain module and the finance expert prepared a PowerPoint presentation with the author’s input and revisions. Meetings were arranged with the technology director for ECHO 360 training and taping. Multiple taping sessions were required to capture quality presentations for financial concerns and burden/strain. The instructional designer uploaded the introductions and the presentations to the topic areas in the educational module.

Websites and Internet resources related to the content outlines were carefully evaluated, and scrutinized using the HON guidelines for developing health information for web-based materials. The guidelines include: authority (qualifications of the author),
complementary (information supports health care provider patient relationship), confidentiality (respect for privacy of personal information), attribution (sources and dates of public information are cited), justifiability (back up for claims of benefits and performance), transparency (accurate email contact), financial disclosure (funding agencies) and advertising and editorial policy (Saba & McCormick, 2006).

Each web link was uploaded to reveal content with one or two mouse clicks. All distracting web site “clutter” was removed. Author and organization credentials were included and easy to identify. The topic presentation outlines and all reading materials were uploaded in pdf format to facilitate printing for users. References were compiled and posted at the end of each module.

**Step 3.** Frequent contact and dialogue was maintained with the Alzheimer’s Association administration and staff in preparation for WBEM evaluation by caregivers. The two male WBEMs on *financial concerns* (Appendix F) and *burden and strain* (Appendix G) were completed first to coincide with a monthly male caregiver support group meeting. The group facilitator personally contacted approximately 20 male caregivers through agency flyers, by telephone and by mail to encourage attendance. All technology equipment was transported by the author to the meeting site to insure consistent module and Internet access. Earphones were provided to reduce auditory distraction. Six male caregivers came to the scheduled support group meeting. The men were asked and agreed to review and evaluate the two male educational modules during the meeting.

**Step 4.** Discussion comments from the male caregiver support group indicated that increasing the font size of some of the reading materials and providing navigation
instructions would facilitate and enhance WBEM use and appeal. The suggestions were incorporated into the development of the female educational modules on communication (Appendix H) and time for self (Appendix I). PowerPoint presentations for female caregivers were produced and taped by the author. The instructional designer uploaded the introductions and the presentations to the topic areas in the WBEM. The criteria for credible websites and Internet resources discussed in Step 2 were consistently followed. References were complied and posted at the end of each module.

**Step 5.** Identifying and scheduling female caregivers of persons with AD to evaluate the female educational modules was accomplished with the assistance of the Alzheimer’s Association administrator and professional contacts. Technology equipment was transported to the caregivers’ preferred locations. Six female caregiver volunteers were invited to review and evaluate the two female WBEMs to insure equal gender evaluation participation. The module reviews and evaluations were conducted in four locations over a period of one week.
Project Evaluation

Evaluation of Implementation

A small convenience sample of male (n=6) and female (n=6) volunteer caregivers of persons with AD was recruited from a northwest Ohio community to evaluate the WBEMs via the Caregiver Evaluation Questionnaire. The questionnaire has three sections: Section 1) demographics, Section 2) 18 closed-ended questions rating the module’s design, clarity/credibility and content and Section 3) five open ended questions about the usefulness of the module for a male or a female (see Appendix F).

Evaluation of the male modules. The male WBEMs, financial concerns and burden and strain, were introduced for evaluation at a male support group meeting at the Alzheimer’s Association office. Six men ages 50-87 years with 15.5 years of education, volunteered to view and evaluate the modules. The men were predominantly White non Hispanic, in good health and cared for spouses or parents as seen in Table 7.

University computers, Ethernet cables, headphones and mouse devices were transported and set up at the Alzheimer’s office prior to the meeting by the author. Three males used individual computers and three males preferred to work in a group and share a fourth computer. The males who worked in the group each had ample opportunity to individually interact with the modules. Each male caregiver viewed the entire content of one module and completed an evaluation questionnaire before viewing and evaluating the second module. Overall, the men were enthusiastic, focused and interested in the module content. One elderly gentleman expressed mild frustration navigating back to the main page but with simple direction returned to the module in earnest.
Table 7

*Caregiver Evaluation Questionnaire: Volunteer Demographics (n=12)*

<table>
<thead>
<tr>
<th></th>
<th>Male Caregivers (n = 6)</th>
<th>Female Caregivers (n = 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (range)</strong></td>
<td>50-87 years</td>
<td>52-76 years</td>
</tr>
<tr>
<td><strong>Education (mean)</strong></td>
<td>15.5 years</td>
<td>15.8 years</td>
</tr>
<tr>
<td><strong>Ethnic background</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black non Hispanic</td>
<td>2 (33.3%)</td>
<td>1 (16.6%)</td>
</tr>
<tr>
<td>White non Hispanic</td>
<td>4 (66.6%)</td>
<td>5 (83.3%)</td>
</tr>
<tr>
<td>American Indian or</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alaska Native</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Asian or Pacific Island</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td><strong>General health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Fair</td>
<td>1 (16.6%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Good</td>
<td>3 (50.0%)</td>
<td>5 (83.3%)</td>
</tr>
<tr>
<td>Very good</td>
<td>2 (33.3%)</td>
<td>1 (16.6%)</td>
</tr>
<tr>
<td>Excellent</td>
<td>0 (00.0%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td><strong>Care recipient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>3 (50.0%)</td>
<td>1 (16.6%)</td>
</tr>
<tr>
<td>Mother</td>
<td>1 (16.6%)</td>
<td>3 (50.0%)</td>
</tr>
<tr>
<td>Father</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
</tr>
<tr>
<td>Mother &amp; father</td>
<td>1 (16.6%)</td>
<td>0 (00.0%)</td>
</tr>
<tr>
<td>Friend</td>
<td>0 (00.0%)</td>
<td>1 (16.6%)</td>
</tr>
</tbody>
</table>

Section 2 responses to the Caregiver Evaluation Questionnaire for the *burden and strain* and the *financial concerns* are reported in Table 8. Scoring in Table 8 is on a 5-1 scale; 5 = Strongly agree; 4 = Somewhat agree; 3 = Neither agree or disagree; 2 = Somewhat disagree; 1 = Strongly disagree. *Total percentages less than 100% indicate caregiver non-response.*
Table 8
Caregiver Evaluation Questionnaire: Two Male Educational Modules

<table>
<thead>
<tr>
<th>Burden (n = 6)</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
<th>Financial Issues (n = 6)</th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appealing colors</td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Print size easy to read</td>
<td>4 (66.6%)</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td>4 (66.6%)</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Appropriate pictures</td>
<td>4 (66.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
<td>2 (33.3%)</td>
<td>2 (33.3%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interesting pictures</td>
<td>4 (66.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
<td>2 (33.3%)</td>
<td>1 (16.6%)</td>
<td>3 (50%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good sound quality</td>
<td>6 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Easy to move through module</td>
<td>2 (33.3%)</td>
<td>2 (33.3%)</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td></td>
<td>3 (50%)</td>
<td>2 (33.3%)</td>
<td></td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Clarity/Credibility</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clear voice</td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td>5 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Concise information</td>
<td>4 (66.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Organized information</td>
<td>4 (66.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Authors clearly stated</td>
<td>3 (50%)</td>
<td>1 (16.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td>4 (66.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Contact information</td>
<td>4 (66.6%)</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td>4 (66.6%)*</td>
<td>1 (16.6%)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Content</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clear topic</td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td>4 (66.6%)*</td>
<td>1 (16.6%)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Useful information</td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td>4 (66.6%)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>New information</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td>2 (33.3%)</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td>1 (16.6%)</td>
<td>3 (50%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interesting information</td>
<td>4 (66.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Easy to understand information</td>
<td>4 (66.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
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</tr>
<tr>
<td>Information can be shared</td>
<td>4 (66.6%)</td>
<td>2 (33.3%)</td>
<td></td>
<td></td>
<td></td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Important to Male Caregivers</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5 (83.3%)</td>
<td>1 (16.6%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The evaluators suggested larger font size, navigation directions and contact information for further dialogue with an expert. Although some evaluators said that some of the information was not new, a majority of the men found the information interesting and useful.

In Section 3, the evaluation responses for the burden and strain module were predominantly positive. All the male caregivers said that the module improved their understanding of caregiver burden and strain. Fifty percent said that the information could be used in their current caregiving situation and 80% said that modules designed for men are helpful “…because we (men) approach things/situations differently.” Fifty percent of the men requested additional content that included: employee assistance and mental health counseling, contact information for dialogue with a professional and a tutorial for module navigation. One man suggested that video-taped speakers refrain from reading to their audience. Final comments included: “the content is great”, “I like it, let’s get it up and working PRONTO” and “the best thing about (this) module is that it meets immediate needs and…can be read and re-read.”

The Section 3 evaluation responses for the financial concerns module were also positive. All the male caregivers said that modules designed for men were helpful. Eighty-three percent of the men commented that the module improved their understanding of financial problems associated with caring for a loved one with AD and 50% said that they could use the information in their current caregiving situation. Additional information was requested for veteran’s benefits and on caregivers who are employed versus retired.
**Evaluation of female educational modules.** The female WBEMs were developed after the male modules were evaluated; therefore, the suggestions for improvement made by the male caregivers, such as larger font size and navigation instructions, were taken into consideration for development of the female modules on *communication* and *time for self*. The women (*n*=6) were ages 52-76 years with 15.8 years of education. They were predominantly White non Hispanic, in good health and cared for spouses, parents and a friend as seen in Table 7. The modules were viewed and evaluated by the female caregivers in four different locations: the Alzheimer’s Association office, a place of employment, a private home and an office at the University.

University computers, Ethernet cables, headphones and mouse devices were transported to each site by the author. All of the female volunteers used individual computers and viewed and completed an evaluation questionnaire for one module before viewing and evaluating the second module. The women were especially enthusiastic, nodding and smiling throughout the experience. Each moved easily through the modules and spent extra time viewing all segments of the modules because as one woman stated she “did not want to miss anything.” The strong positive results of Section 2 of the Caregiver Evaluation Questionnaire for the *communication* and *time for self* are reported in Table 9. Scoring is on a 5-1 scale; 5 = Strongly agree; 4 = Somewhat agree; 3 = Neither agree or disagree; 2 = Somewhat disagree; 1 = Strongly disagree. *Total percentages less than 100% indicate caregiver non-response.*
Table 9

*Caregiver Evaluation Questionnaire: Two Female Educational Modules*

<table>
<thead>
<tr>
<th>Communication (n = 6)</th>
<th>Design</th>
<th>Clarity/Credibility</th>
<th>Content</th>
<th>Important to Female Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appealing colors</td>
<td>4 (66.7%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Phrases easy to read</td>
<td>5 (83.3%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Adequate pictures</td>
<td>5 (83.3%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Interesting pictures</td>
<td>5 (83.3%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Good sound quality</td>
<td>4 (66.7%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Easy to move through module</td>
<td>5 (83.3%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Time for Self</td>
<td>4 (66.7%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
<tr>
<td>Time for Others</td>
<td>4 (66.7%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
<td>6 (100%)</td>
</tr>
</tbody>
</table>
Section 3 evaluation responses for the *communication* module were very positive. All the female caregivers reported that the module improved their understanding of communication strategies. One-hundred percent of the women said that the information could be used in their current caregiving situation, “wonderful suggestions…I love this module” and “…giving dad time to process his thoughts and not hurry him” maintains dignity. Eighty-three percent said that modules designed for women are helpful “(because) perhaps our (women’s) needs are different” and “I see a difference between the way my brother and I care give.” Sixteen percent (one female) suggested information be added on the importance of using memories and past experiences to elicit cooperation. Final comments included: “vignettes are helpful and give good information”, “explanations on how to communicate are useful and relatable”, “the idea of showing a person a card or picture to help them understand was very good,” and fabulous … clearly the most important area in the caregiving experience.”

Section 3 evaluation responses for the *time for self* module were also very positive. All female caregivers agreed that the module helped them understand the importance for personal time and found the information useful in their current caregiver situation to “take more time without feeling the guilt”. One hundred percent of the females thought modules designed for women are helpful because “men and women are coming from entirely different directions in terms of how they perceive things…our roles and how we can help ourselves need to be personalized” and “men and women…see thing differently because that is how we are made”. One woman did not like the grey color choice for the *time for self* presentation but another liked the progression from grey to muted colors. Additional comments included: “the topics were well covered,” “the
personal health assessment is useful … (as is the) guide to taking care of yourself ... the exercise video is very good” and “links for choices are very good…easy to move around and find what fits, print interesting and videos appropriate.”

Evaluation Summary

Interventions aimed at supporting and/or providing information to caregivers of persons with AD have varying effects on individual caregiver needs (Thompson et al., 2007); therefore, matching interventional strategies that target specific caregiver populations (gender) may be beneficial (Gitlin, Burgio, Mahoney, Burnes, Zhang, Schulz et al., 2003). Web-based interventions promoting health and emotional well-being hold promise for meeting psychosocial and emotional needs of adult caregivers (Glueckauf, Ketterson, Loomis & Dages, 2004). Internet technology offers “great promise for facilitating some of the responsibilities that caregivers shoulder and more generally to improve the care of their recipients” (NAC/AARP, 2009, p. 20). Helping caregivers manage responses to caregiving reduces strain and depression, improves physical health and family quality, improves care-recipient health and well-being and reduces adverse events (Capezuti et al., 2008).

Gender specific WBEMs are an innovative approach to providing caregiver support and reduce some of the incongruence caregivers of persons with AD experience. The review of the literature found men and women are affected by and approach caregiving differently and this finding was supported in qualitative comments by both the male and female caregiver evaluators. The male and the female responses to WBEMs were overwhelmingly positive. Both men and women demonstrated enthusiasm using the gender specific modules, offered helpful suggestions for improvement and expressed
interest in further development and availability of such a resource online. The average time each volunteer spent reviewing each module was one hour. In general, the females navigated through the modules easier than the men. Suggestions for larger font size and navigation instructions from the men were used to design the female modules with good results.
Project Findings

The goals for this EBP project were 1) to identify gender differences in problems reported by caregivers of person with AD and 2) to develop gender specific WBEMs to help caregivers of persons with AD cope with these problems (restore congruence). The following discussion substantiates how these goals were met.

**Findings related to the implementation process.** The professional support for this project from the University and the local Alzheimer’s Association was exceptional. The selected team members were enthusiastic, cooperative, manageable, effective and productive. The professional and technology resources were available and without cost and caregiver recruitment was facilitated by the Alzheimer’s Association. By following HON guidelines for developing health information for web-based materials (Saba & McCormick, 2006), general considerations for developing written education materials (Pierce, 2010), web-based template guidelines (Lohr & Ku, 2003), and the National Institute on Aging and the National Library of Medicine usability factors for web-based programs (Chaffin & Maddux, 2007), the gender specific WBEM template design and educational content were well received by the caregiver evaluators. The simplicity of accessing the topic modules and uncluttered supporting web links, in various locations and environments demonstrated the potential for using the modules in a variety of clinical and community settings. Improvements to the current template include an introductory web page, a navigation tutorial and biographical information for author and expert contributors.

**Findings related to impact.** From a systems perspective, this project was facilitated through University technology and resource support. Overburdened caregivers
have limited time and energy to contribute to projects and are often reluctant to “take on one more task” such as participation in projects; therefore, the interest and assistance in caregiver recruitment from the local Alzheimer’s Association was crucial. This project stimulated interdisciplinary collaboration opportunities among nursing, medicine, social services, instructional design, technology and community leaders. Nurse practitioner interprofessional collaboration and dissemination of research and EBP project findings are advanced practice competencies defined in the Essentials of Doctoral Education for Advanced Nursing Practice document (American Association of Colleges of Nursing, 2006) and are nursing standards of practice in protocols for family caregiving (Capezuti et al., 2008). Interprofessional collaboration and dissemination of findings are well aligned with the goals of this EBP project.

**Project outcomes.** Project outcomes are population-relevant “consequences of the intervention” (DiCenso, Guyatt, & Ciliska, 2005, p.24). This project identified gender differences in how caregivers of persons with AD (population) approach and are affected by the caregiving problems and developed gender specific WBEMs to provide educational and emotional support (intervention). The Framework of Systemic Organization guided this nursing interventional project. Friedemann (1995) writes, “families who want to continue care …may benefit from resources that ease their task … (and discover) ways to maintain the wholeness of the patient…and find satisfaction through individuation” (p. 266). Individuation is a process that allows new information to enter the family system helping to restore balance or congruence and easing the consequences of long term caregiving (Friedemann, 1995, 2010). Individual interventions were found to be more effective than group interventions in improving
caregiver well-being (Sorenson et al., 2002). Caregivers who feel supported can maintain personal energy and health and subsequently can provide care for longer periods of time. Improving caregiver well-being is reported to delay nursing home placement of persons with AD up to 1.5 years reflecting an annual cost savings of $102,000 per patient (Mittelman, Haley, Clay & Roth, 2006; MetLife, 2010). The overwhelmingly positive responses reported in the caregiver evaluations of the gender specific WBEMs for clarity, functionality and utility provide measurable data that indicate the potential usefulness and cost effectiveness of this EBP project.

There are a few limitations identified for this project. The strength of the level of evidence (LOE) for most of the evidence on gender differences from the literature was a Level IV (non-experimental studies) on a Level I (systematic reviews) to Level VI (experts/consensus panels) scale. The small sample size of the CNA-D caregiver assessment group ($n=10$) and the small sample size ($n=12$) of caregiver evaluators, limited sample diversity and a single community setting were limitations; furthermore, all caregiver evaluators were already seeking support through the Alzheimer’s Association. Computer literacy was a limitation for the assessment group. There may have been some caregiver bias during module review and evaluation as the volunteers interacted with the author. Finally, the limitations of ECHO 360 in terms of sound and video capture quality and the mild anxiety demonstrated by the presenters during taping limited the quality of the presentations.

**Clinical significance and future steps.** There are currently 15 million informal caregivers of persons with AD in the U.S. who provide over 17 billion hours or $202 billion in unpaid care; by 2050, Medicare costs for persons with AD will increase by
600% and Medicaid costs will increase by 400% (Steenhuysen, 2011). The need for cost effective, efficient interventions that support caregivers is imperative. Educational interventions improve caregiver well-being and coping skills (Acton & Kang, 2001; Sorenson et al., 2002). Caregivers who are supported can provide more competent care over longer periods of time. WBEMs have the potential to be accessed by and offer support to large numbers of national and international caregivers at their convenience without travel expense or interruption in care work.

In clinical and community settings, DNP practitioners are prepared to “design, direct and evaluate quality improvement methodologies to promote safe, timely, effective, efficient, equitable and patient centered care” (AACN, p.12). Combining caregiver assessment with technology driven gender specific educational interventions has potential to improve the quality of life of both the caregiver and the care receiver. Additionally, DNP practitioners can work with other healthcare professionals in practices and community settings to promote technology driven, innovative caregiver interventions and advocate for caregiver recognition in the health care system. DNP practitioners have the ability to “assume broad leadership roles on behalf of the public as well as the nursing profession” and to integrate practice experiences by analyzing health care policies and engaging in politically competent action (AACN, 2006, p. 13). Current health care reform laws passed in March of 2010 that expand financial support for caregiver services, training, care coordination and long-term services require active support from expert healthcare practitioners to avoid projected budget cuts. This is an essential advocate responsibility for DNP practitioners to embrace.
Gender specific information was well received by the caregivers involved in this project and supported literature findings that men and women differ in how they recognize and react to caregiving problems. The modules provided an individualized approach and pace to learning and support. Additionally, WBEMs are designed for delivery in a variety of settings from private homes, clinical settings, nursing homes, geriatric centers, libraries, agencies, and workplaces. There is potential for the modules to be available on mobile devices, DVDs, audio tapes and in printed handout format. Caregivers with basic computer skills were able to navigate through each module with minimal instruction. Although, 79% of American adults use the Internet (Pew Internet and American Life project, 2010) there are caregivers who are not computer literate. The flexibility of the module template could be adapted to other modalities for use by caregivers without computer skills.

The project finding that men and women respond well to gender based information is a strategy that individualizes caregiver support and can be expanded to develop additional modules on other problems/needs of caregivers of persons with AD. The local and regional Alzheimer’s Associations have interest in loading the modules on their Alzheimer’s coaching website. Other organizations that provide services for caregivers of other chronic illnesses may also find the module template helpful. Future projects and research could focus on the theoretical perspectives of gender, larger sample sizes and on diverse populations.

**Formal reports and dissemination.** This manuscript documents the scope of this EBP project and is the first step in disseminating the phases of project development, implementation and findings to stakeholders, academic institutions and other
professionals. The project was presented as a poster presentation at the Midwest Nursing Research Society (MNRS) conference in March, 2011 and was awarded the first place “DNP Student Poster Award” for content and design. This conference provided an opportunity to share the project findings with other nursing researchers and professionals and provided the author with an invitation to submit a manuscript on this project in the *Western Journal of Nursing Research*. The author plans to pursue this opportunity.

Plans are in place to present a paper at the April, 2011 Nursing Research Day Conference at the University of Toledo, College of Nursing and to undergraduate nursing students in July, 2011 at the University. Abstracts for poster presentations will be submitted to the Ohio Association of Advanced Practice Nurses conference (OAAPN), the Sigma Theta Tau (STTI) research conference and the Rehabilitation Nursing Foundation (RNF) conference. The author is invited to write a column about the project in the *Association of Rehabilitation Nursing Foundation Newsletter*. This newsletter reaches over 6500 rehabilitation nursing members. Additional manuscripts may be submitted in the future to *Alzheimer’s Care Quarterly* and the *Rehabilitation Nursing Journal*. The Alzheimer’s Association will be contacted with an offer to present the study findings to staff and interested caregivers. Other opportunities to disseminate the project findings will continue to be explored.
Final Summary

This EBP project identified gender differences in problems (incongruence) reported by caregivers of persons with AD and developed gender specific WBEMs to help caregivers cope with these problems. Two forms of evidence, research literature \((n=9)\) and caregiver assessment \((n=10)\) determined the key problems prevalent in male and female caregivers. WBEMs were developed for men on burden and strain and financial concerns and for women on communication and time for self and evaluated by a second group of caregivers \((n=12)\). Caregivers’ response was overwhelmingly positive to the “one stop shopping” the modules provided. Gender specific WBEMs are an efficient way to stabilize the internal system of a caregiver, the external system of the family and restore congruence in a caregiver situation. Providing caregiver support can delay nursing home placement of a loved one with AD by 1.5 years reflecting a cost savings of \$102,000 per person. WBEMs have the potential to provide caregiver support to hundreds of caregivers throughout the nation who access the Internet searching for problem solutions and support.

Although there are multiple interventional caregiver support strategies reported in the literature (respite care, counseling, psychoeducation and support groups), education is among the proven strategies used to improve the quality of life for caregivers of persons with Alzheimer’s disease. The gender specific WBEMs could be combined with other interventional strategies to form multi-component interventions in the future. This project developed modules for four caregiver problems but additional gender specific modules could be developed to address the 14 remaining caregiver problems included in the CNA-D instrument.
The gender specific WBEMs can be produced at a relatively low cost. The projected development cost of one module is approximately 3% of the cost to institutionalize a loved one with AD for 18 months in a nursing home. Furthermore, the module template can be adapted to create WBEMs for caregivers of persons with other chronic illnesses. As leaders in healthcare, doctorate prepared nurse practitioners have expertise to assess caregivers in the clinical setting, identify caregiver problems and design innovative approaches to help caregivers provide competent home care. Gender specific WBEMs provide unique support to male and female caregivers and offer a cost effective, efficient, convenient strategy to deliver caregiver support in homes, the clinical settings and communities.
References


### Appendix A
Review of the Literature: Caregiver Needs / Problems

<table>
<thead>
<tr>
<th>Authors</th>
<th>Type of study</th>
<th>Evidence Level</th>
<th>Number of Participants</th>
<th>Pertinent study findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Edelman et al., 2006</td>
<td>Non-experimental</td>
<td>IV</td>
<td>Caregivers = 100 Care receivers = 100</td>
<td>Caregiver care recipient educational needs differ; patient family education and services should be individualized; caregiver top 5 service/information needs – legal/financial planning, dealing w/friends &amp; family, long-term care, alternative medicine /tx and genetics of AD</td>
</tr>
<tr>
<td>Nichols et al., 2006</td>
<td>Secondary analysis of RCT data</td>
<td>II</td>
<td>n = 165</td>
<td>Clinical characteristics of caregivers and care recipients affected behavioral and stress and coping needs; caregivers selected educational topics</td>
</tr>
<tr>
<td>Wackerbarth &amp; Johnson, 2002</td>
<td>Non-experimental Descriptive survey</td>
<td>IV</td>
<td>n = 128</td>
<td>Diagnosis/ treatment information, legal/financial issues more important than general disease information; health plan coverage most important; females need more support information than males</td>
</tr>
<tr>
<td>NAC/AARP, 2009</td>
<td>Non-experimental</td>
<td>IV</td>
<td>n = 1480</td>
<td>Fourteen major caregiver support and information needs were identified</td>
</tr>
</tbody>
</table>
Appendix A  
Review of the Literature: Gender Differences

<table>
<thead>
<tr>
<th>Authors</th>
<th>Type of study</th>
<th>Evidence Level</th>
<th>Number of Participants</th>
<th>Pertinent study findings</th>
</tr>
</thead>
</table>
| Bedard et al., 2005  
*AD = Alzheimer disease* | Non-experimental Descriptive | IV | \(n = 557\) | Males & females caregivers may experience different role burden requiring gender specific interventions |
| Calasanti et al., 2007  
*AD* | Qualitative “constructivist” | *IV* | \(n = 9\) | Husbands & wives same tasks same sentiment; male caregiving rooted in “sense of selves as men” |
| Chiou et al., 2005 | Non-experimental Descriptive survey comparative | IV | \(n = 388\)  
\(f = 280; m = 108\) | More female than male caregivers had negative health problems; consideration needed for gender differentiating in caregiving |
| Ford et al., 1997  
*AD* | Non-experimental Descriptive | IV | \(n = 197\) | No gender differ in stressfulness; gender role less important than nature of stressor; caregiver distress greater for dangerous behavior & aggression |
| Garity, 1997  
*AD* | Non-experimental Descriptive | IV | \(n = 76\) | Females experience more burden and personal strain due to multiple roles (mother, wife, worker, caregiver) Learning styles differ between genders men had more diverse learning styles than women |
| Guberman et al., 2006 | Qualitative Multiple-case design | *IV* | \(n = 75\) | Practitioners are aware of difficulties caregivers face but have high expectations of caregivers in treatment plans ignoring difficulties & impact on family |
| Luchetti et al., 2009  
*AD* | Non-experimental Descriptive correlation | IV | \(n = 99\) | Restricted personal time and sense of failure regarding hopes and dreams were related to caregiver burden; interventions directed in these areas could reduce burden (respite care, day care, counseling) |
<p>| Navaeie-Waliser et al., 2002 | Non-experimental Correlational | IV | (n = 1002) | More female than male caregivers provide care &amp; experience more stress &amp; burden; support needed to reduce family strain |</p>
<table>
<thead>
<tr>
<th>Authors</th>
<th>Type of study</th>
<th>Evidence Level</th>
<th>Number of Participants</th>
<th>Pertinent study findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Papastavrou et al., 2009 AD</td>
<td>Non-experimental Cross sectional Descriptive</td>
<td>IV</td>
<td>$n = 172$</td>
<td>Female caregiver had significantly higher levels of burden and depression than male caregivers; female coping strategies are significantly emotionally focused (example: denial)</td>
</tr>
<tr>
<td>Pinquart &amp; Sorensen, 2006</td>
<td>Meta-analysis</td>
<td>I</td>
<td>$n = 229$ studies</td>
<td>Small gender differences but women had higher levels of burden &amp; depression – lower levels of well being &amp; health; Women cared for more behavioral problems &amp; provided more caregiving hours</td>
</tr>
<tr>
<td>Sugiura et al., 2009 AD</td>
<td>Non-experimental Descriptive survey</td>
<td>IV</td>
<td>$n = 308$ $(m = 135; f = 173)$</td>
<td>Spousal caregiving in Japan – women caring for spouses had higher depression scores, performed higher level care, accepted their role, did not seek to share caregiving but sought emotional support</td>
</tr>
<tr>
<td>Sun et al., 2008 AD</td>
<td>Non-experimental descriptive</td>
<td>IV</td>
<td>$n = 720$ $(m = 165; f = 555)$</td>
<td>Female caregivers less likely to use in-home services and used more public transportation services (less comfortable driving spouses with dementia)</td>
</tr>
<tr>
<td>Thompson et al., 2004 AD</td>
<td>Non-experimental Correlation</td>
<td>IV</td>
<td>$n = 61$ $(m = 16; f = 45)$</td>
<td>Female caregivers more physical manifestation of stress than men</td>
</tr>
<tr>
<td>Rabinowitz &amp; Gallagher-Thompson, 2007 AD</td>
<td>Non-experimental Descriptive</td>
<td>IV</td>
<td>$n = 256$</td>
<td>All female participants: Latino caregivers ate less but gained more wt than Caucasian; More Caucasians smoked &amp; had HD *first study to examine ethnic/kinship status differences in health behaviors</td>
</tr>
</tbody>
</table>
## Appendix A

### Review of the Literature: Caregiver Assessment

<table>
<thead>
<tr>
<th>Authors</th>
<th>Type of study</th>
<th>Evidence Level</th>
<th>Number of Participants</th>
<th>Pertinent study findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Czaja et al., 2009 AD</td>
<td>Secondary analysis</td>
<td>II</td>
<td>( n = 642 )</td>
<td>The Risk Appraisal Measure (RAM) show promise as an assessment tool for caregivers of persons with dementia. Assess six caregiver risk domains: depression, burden, self-care and health behavior, social support, safety and patient problem behaviors.</td>
</tr>
<tr>
<td>Guberman et al., 2007</td>
<td>Non-research Expert opinion</td>
<td>V</td>
<td></td>
<td>Review of three studies use of the CARE tool; recommend clear rational for carer assessment &amp; approach to long term care</td>
</tr>
<tr>
<td>Keefe et al., 2008</td>
<td>Non-experimental Descriptive and Qualitative</td>
<td>IV</td>
<td>( n = 349 )</td>
<td>The CARE assessment tool assists in practitioners understanding what it means to be a caregiver &amp; caregiver key concerns are identified quicker</td>
</tr>
<tr>
<td>Wancata et al., 2005 AD</td>
<td>Focus group &amp; interview for inter-rater and test re-test reliability Correlations with Zarit Burden inventory</td>
<td>NA</td>
<td>( n = 45 ) dementia caregivers, ( n = 40 ) caregivers, ( n = 40 ) professionals</td>
<td>The CNA-D validity and reliability scores (Cronbach’s ( \alpha ) and ( k ) values) indicate the instrument is a valid and reliable tool for comprehensive assessment of caregivers of persons with dementia</td>
</tr>
</tbody>
</table>
### Appendix A
Review of the Literature: Caregiver Interventions

<table>
<thead>
<tr>
<th>Authors</th>
<th>Type of study</th>
<th>Evidence Level</th>
<th>Number of Participants</th>
<th>Pertinent study findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acton &amp; Kang, 2001</td>
<td>Meta-analysis</td>
<td>I</td>
<td><em>n = 24 research reports</em></td>
<td>Analyzed Twenty-seven (27) intervention strategies for burden; multi-component interventions significantly reduced burden; burden as an outcome may be too global to consistently affected by intervention</td>
</tr>
<tr>
<td>Acton &amp; Winter, 2002</td>
<td>Summative Research Review</td>
<td>I</td>
<td><em>n = 73 research reports</em></td>
<td>1999-2001 nursing and non-nursing research review of interventions for family members caring for demented elderly; significant burden reduction was reported for education, support groups and case management</td>
</tr>
<tr>
<td>Garity, 1997</td>
<td>Non-experimental Descriptive</td>
<td>IV</td>
<td><em>n = 76</em></td>
<td>Learning styles differences should be considered when planning support.</td>
</tr>
<tr>
<td>Gitlin et al., 2003</td>
<td>Experimental meta-analytic</td>
<td>I</td>
<td><em>n = 1222</em></td>
<td>6 month follow-up – design unable to determine which interventions reduce caregiver burden; insight and no single intervention meets the multiple stressors of caregiving for persons with dementia</td>
</tr>
<tr>
<td>Hepburn et al., 2001</td>
<td>Experimental Random assignment</td>
<td>II</td>
<td><em>n = 117</em></td>
<td>Caregiver role training benefits caregivers; reduced burden, depression and reaction to care receiver behavior problems</td>
</tr>
<tr>
<td>Kaufman et al., 2010</td>
<td>Non-experimental Cross sectional survey</td>
<td>IV</td>
<td><em>n = 141</em></td>
<td>Two dimensions of social support improve feelings of life satisfaction for rural caregivers 1) someone to talk to or socialize with 2) positive regard from others</td>
</tr>
<tr>
<td>Paun et al., 2004</td>
<td>Experimental Descriptive qualitative</td>
<td><em>IV</em></td>
<td><em>n = 115</em></td>
<td>Care recipient, caregiver and resource issues emerged; Skill development must include synergy and transformative process along with knowledge and time to reach emotional acceptance “emotional acceptance of their loved one as a new person suffering from an incurable disease”</td>
</tr>
<tr>
<td>Authors</td>
<td>Type of study</td>
<td>Evidence Level</td>
<td>Number of Participants</td>
<td>Pertinent study findings</td>
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<td>-------------------------</td>
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<td>------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Sorensen et al., 2002</td>
<td>Meta-analysis</td>
<td>I</td>
<td>( n = 78 ) caregiver interventions</td>
<td>Combined interventions produced significant improvement for caregiver burden, depression, subjective well-being, ... effects modified by gender and relationship to care receiver; intervention effects were smaller for dementia caregivers than other caregivers</td>
</tr>
<tr>
<td>Schutlz et al., 2002</td>
<td>Summative Research Review since 1996</td>
<td>I</td>
<td></td>
<td>Reviewed caregiver intervention outcome studies for clinical significance; clinical and statistical significance is of value in the area of caregiver research</td>
</tr>
<tr>
<td>Schultz, et al., 2005</td>
<td>Summative Research Review RCTs (1999-2005)</td>
<td>I</td>
<td>( n = 41 ) dementia caregiver studies; ( n = 10 ) stroke caregiver studies</td>
<td>All interventions focused on family members and combined educational materials with counseling and skills training with consistent effects in reducing depression, burden and anxiety; AAGP recommendation: “family/caregiver counseling is medically necessary and should be a reimbursable, covered service”</td>
</tr>
<tr>
<td>Thompson et al., 2007 AD</td>
<td>Systematic Review of RCTs</td>
<td>I</td>
<td>( n = 44 ) studies</td>
<td>Little evidence that support and or information interventions for dementia caregivers are uniformly effective; suggest evaluating interventions for outcomes that are important to clinicians and carers; four technology-based studies included</td>
</tr>
<tr>
<td>Zarit, 2008</td>
<td>Expert Opinion</td>
<td>V</td>
<td></td>
<td>Burden associated with care of dementia persons is multidimensional and varies with the individual caregiver; education, skill training, family and paid support are effective strategies to reduce burden and improve caregiver QOL</td>
</tr>
</tbody>
</table>
### Appendix A
Review of the Literature: Web-based Interventions

<table>
<thead>
<tr>
<th>Authors</th>
<th>Type of study</th>
<th>Evidence Level</th>
<th>Number of Participants</th>
<th>Pertinent study findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beauchamp et al., 2005</td>
<td>Quasi experimental</td>
<td>III</td>
<td>n = 299</td>
<td>Participants who viewed the web intervention reported reduced caregiver strain and improved self-efficacy, etc. 30 days post exposure; interactive multimedia internet interventions are low-cost, effective, convenient learning opportunities</td>
</tr>
<tr>
<td>Fenton et al., 2007</td>
<td>Program evaluation</td>
<td>V</td>
<td></td>
<td>CareNet is an interactive web based caregiver support project to provide access to support channels to informal caregivers and practice communities</td>
</tr>
<tr>
<td>Galvin et al., 2010</td>
<td>Non-experimental</td>
<td>IV</td>
<td>n = 962</td>
<td>Lewy Body dementia caregivers 88% women; rarely used supportive services; reported preferences for web based information;</td>
</tr>
<tr>
<td>Glueckauf et al., 2004</td>
<td>Quasi-experimental</td>
<td>III</td>
<td>n = 21</td>
<td>Preliminary results indicated that online cognitive-behavioral interventions (Positive Caregiving classes) may lead to substantial reduction in caregiver burden and increase confidence in caregiving behaviors. Internet and telephone based interventions hold considerable promise.</td>
</tr>
<tr>
<td>NAC/AARP, 2009</td>
<td>Non-experimental</td>
<td>IV</td>
<td>n = 1480</td>
<td>Fourteen major caregiver support and information needs, were identified; sources used for caregiving information and support for caregivers #1 Healthcare professional and #2. Internet; Technology supported</td>
</tr>
<tr>
<td>Wantland et al., 2004</td>
<td>Meta-analysis</td>
<td>I</td>
<td>n = 22</td>
<td>Improvement in outcomes for individuals using web-based interventions to achieve specified knowledge and or behavior change for the studied outcomes</td>
</tr>
</tbody>
</table>
## Appendix B
### A Comparison of Caregiver Assessment Instruments

<table>
<thead>
<tr>
<th>Caregiver Assessment Areas</th>
<th>USA Calif</th>
<th>USA Mass</th>
<th>USA Minn</th>
<th>USA Penna</th>
<th>USA Wash</th>
<th>*AMA</th>
<th>Austria (CNA-D tool)</th>
<th>Canada (C.A.R.E. tool)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability to provide care</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Care duration</td>
<td>X</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
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<tr>
<td>Care Frequency</td>
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<td>x</td>
<td>x</td>
<td>x</td>
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<td>Demographic Information</td>
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<td>x</td>
<td>x</td>
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<tr>
<td>Information/Education needs</td>
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<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Long distance care</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Mental health</td>
<td>X</td>
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<td>x</td>
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<td>x</td>
<td></td>
</tr>
<tr>
<td>Physical health</td>
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<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
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<tr>
<td>Social support</td>
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<td>x</td>
<td>x</td>
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<td></td>
<td></td>
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<tr>
<td>Strain</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
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<tr>
<td>Willingness to provide care</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>CR driving status; distance between CG/CR</td>
<td>legal, health insurance, financial status</td>
<td>Supply availability Distance between CG/CR</td>
<td>Distance between CG/CR</td>
<td>CG: insomnia, depression, work issues, ↓ concentration</td>
<td>CG: legal issues Financial burden Disappointment Communication Danger situations Discrimination Burn out, isolated</td>
<td>CG: describe responsibilities; concerns, relationships, Crisis/future planning</td>
<td></td>
</tr>
</tbody>
</table>

- CG = caregiver
- CR = care receiver

### Caregiver Instrument Focus

<table>
<thead>
<tr>
<th>Caregiver Instrument Focus</th>
<th>USA Calif</th>
<th>USA Mass</th>
<th>USA Minn</th>
<th>USA Penna</th>
<th>USA Wash</th>
<th>*AMA</th>
<th>Austria (CNA-D tool)</th>
<th>Canada (C.A.R.E. tool)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient focus w/ Caregiver assessment component</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver specific</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Self assess *x</td>
<td>X</td>
</tr>
<tr>
<td>Dementia Caregiver specific</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

*Adapted from Domains of Caregiver Assessment Tools by State, (Feinberg, Wolkwitz, & Goldstein, 2006, p. 10).*
Appendix C
CNA-D Instrument: Web-based Format

Caregiver Assessment

A member of your family is suffering from a form of dementia, for example Alzheimer’s disease. Some relatives and caregivers have reported that they have burdens and worries because of the illness of their family member. Some caregivers have also voiced their need for more or better support.

We would like to try to take the experiences and wishes of caregivers into account in planning services that meet the needs of caregivers and their families. Therefore, we would like to invite you to share your worries, burdens, and problems with us.

In the following survey, you will find a number of different problem areas described. Not all of these problem areas may apply to your specific situation, however.

Of course all information will be treated confidentially.

Thank you very much for your help!

Please answer the following statements by putting in a word or number in the blank space or by filling in the circle.

The following questions are about you.

1. My first name is:

2. My age is: [insert number] years.

3. I am:
   - Male
   - Female

4. My ethnic background is:
   - American Indian or alaska native
   - Asian or pacific islander
   - Black, not of hispanic origin
   - Hispanic origin
DEVELOPING GENDER SPECIFIC WEB-BASED

○ White, not of hispanic origin
○ Other or unknown

5. I have completed [insert number] years of schooling, including college.

6. In general, my health is:

○ Poor
○ Fair
○ Good
○ Very good
○ Excellent

7. The person that I care for is my:

○ Wife
○ Husband
○ Mother
○ Father
○ Brother
○ Sister
○ Friend
○ Other

8. Specify: ______________________

9. I have been caring for this person for: [insert number] months.

The following questions are about the person you care for who has dementia.

1. The age of the person I care for is: [insert number] years.

2. His or her diagnosis is: ______________________
3. His or her ethnic background is:
   - American Indian or Alaska native
   - Asian or Pacific Islander
   - Black, not of Hispanic origin
   - Hispanic origin
   - White, not of Hispanic origin
   - Other or unknown

4. He or she lives:
   - With me
   - With the family
   - In an apartment
   - In assisted living or a nursing home
   - In his or her own home

Please read the following questions and rate them as to whether they are a problem for you or not.

1. Are you sufficiently informed about the illness, its symptoms, and its course?

   Consider the following to help you rate this question:
   - Do you know which illness (diagnosis) your afflicted family member has?
   - Do you know what this diagnosis means?
   - Do you know enough about symptoms, course, and prognosis of this illness?
   - Do you know of factors that worsen the symptoms of this illness? (e.g., changes in daily routines)

Check one of the choices below:

   - No problem or mild problem
   - Moderate problem
   - Serious problem
   - Not known or insufficient information
2. Are you sufficiently informed about the treatment?

Consider the following to help you rate this question:

- Do you know what type of treatment (e.g. medication, cognitive training) the patient needs?
- Are you sufficiently informed about the effects and unwanted side effects of this medication?
- Do you know for how long this medication will need to be taken?
- Do you know which medications can occasionally be taken as needed?
- Do you know how you can supply yourself with medication and nursing materials (e.g. bandages, diapers etc.)?

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

3. Are you sufficiently informed about the services providing help for patients living in private households?

Consider the following to help you rate this question:

- Are you sufficiently informed about services that can support you in caring for the patient? (e.g. mobile nursing care, meals-on-wheels, transportation services)
- Do you know where you can get this help? Do you know where you can apply for it?
- Do you know how much these services cost?

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

4. Do you have financial difficulties because of the patient? Are you aware of financial benefits you or the patient are entitled to?
Consider the following to help you rate this question:

- Do you have financial burdens,
  - Because you had to give up or reduce work in order to take care of the patient?
  - Because you have to pay people to help you take care of the patient (e.g. a nurse)?
  - Because of high expenditures for the patient (medication, nursing material, transportation etc.)
  - Because the patient loses money or other valuables?
  - Because of other costs caused by the patient (e.g. repairs in the household)

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

5. Are you experiencing difficulties because the patient can no longer handle some of his private legal business and you have to take care of it for him/her?

Consider the following to help you rate this question:

- Are you sometimes experiencing difficulties,
  - because the patient no longer understands contracts and you have to take his place?
  - because the patient has signed legally binding documents without really having understood their contents (i.e. missing legal capacity)?
  - because you have to act on behalf of the patient and represent him/her in front of authorities, and you no longer know how to do that?
  - because the patient has lost his feeling for the value of money and spends large amounts?
  - Do you have full legal power enabling you to represent the patient in these cases?

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information
6. Are you sometimes sad or disappointed because of the illness and its course? Do you sometimes worry about what the future might hold for the patient?

Consider the following to help you rate this question:
- Do you sometimes feel disappointed or hopeless,
  - Because the illness worsens despite treatment?
  - Because the patient seems like a complete stranger to you at times?
  - Because the patient does not recognize you or other members of the family (or gets them mixed up with other people) at times?
  - Because you can no longer communicate with the patient like you used to?
  - Because the patient can no longer take care of himself/herself and has lost many of his skills?
  - Because the patient is completely dependent on you?
- Do you sometimes worry about how living with the patient will work in the future?
- Do you sometimes worry about what will happen to the patient in case you are unable to take care of him/her?

Check one of the choices below:

- [ ] No problem or mild problem
- [ ] Moderate problem
- [ ] Serious problem
- [ ] Not known or insufficient information

7. Are you experiencing difficulties communicating with and handling the patient?

Consider the following to help you rate this question:
- Do you sometimes feel doubtful when dealing with the patient?
- Do you sometimes not know how to react when the patient behaves in a way he/she never used to (e.g. because of hallucinations, aggression, or delusions)?
- Are you sometimes not sure whether you should do the patient’s chores for him/her or let him/her try to do them as a challenge?
- Do you frequently experience conflicts or tension with the patient?
- Are you sometimes angry with the patient?
- Are you able to:
  - avoid escalation of tense situations,
  - deal with the patient’s fears?
  - calm tense situations?
  - find a balance between too much or too little consideration of the patient’s needs?
  - realize, which kind of behavior can be attributed to the illness?
Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

8. Does the patient sometimes behave toward you in ways that burdens you?

Consider the following to help you rate this question:
- Does the patient sometimes not allow you to help him/her, for example while trying to feed him/her, helping him/her get dressed, or while helping him/her with personal hygiene?
- Are you sometimes under the impression that the patient does not at all appreciate what you are doing for him/her? Is he/she sometimes aggressive toward you?
- Does the patient sometimes display inappropriate sexual behavior?
- Do you sometimes feel like the patient is putting you under pressure (e.g. because the patient is very demanding)?

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

9. Did you experience any critical situations at home during the last 3 months?

Consider the following to help you rate this question:
- During the last 3 months:
  - Have there been any situations with the patient which got totally out of control?
  - Was there a situation where you had the feeling that the patient urgently needs medical care but you could not convince him/her to seek it?
  - Was there a situation where you felt threatened by the patient or where the patient was aggressive?

Check one of the choices below:

- No problem or mild problem
10. Do you have enough time for yourself? Does somebody else help you with the patient in case you have other obligations?

Consider the following to help you rate this question:
- Do you have too little time for yourself because you have to take care of the patient?
- Do you sometimes have difficulties keeping appointments or doing the shopping because you do not dare to leave the patient alone?
- Have you not gone on vacation because you had to take care of the patient?
- Does somebody else take care of the patient for you, when you are ill yourself or are unable to take care of him/her for other reasons? Have you had problems in this regard during the last 3 months?

Check one of the choices below:
- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

11. Has the illness caused you to see other people less often or has it led to tension in the family?

Consider the following to help you rate this question:
- Do you have too little time for yourself because you have to take care of the patient?
- Do you sometimes have difficulties keeping appointments or doing the shopping because you do not dare to leave the patient alone?
- Have you not gone on vacation because you had to take care of the patient?
- Does somebody else take care of the patient for you, when you are ill yourself or are unable to take care of him/her for other reasons? Have you had problems in this regard during the last 3 months?

Check one of the choices below:
- No problem or mild problem
12. Are there situations where you fear danger for the patient?

Consider the following to help you rate this question:
- Does the patient tend to leave the house alone and then not find his way back home?
- Has the patient injured himself/herself at home or have there been situations were the patient was at risk for injury? (e.g. hot stove)
- Does the patient often not drink enough or eat too little? Does the patient not have a well-balanced diet?

Check one of the choices below:
- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

13. Are you afraid that other people might find out about your family member’s illness? Have you heard things about the psychiatric care system or about nursing homes that upset you?

Consider the following to help you rate this question:
- Are you afraid to tell other people that a member of your family is suffering from dementia and is in need of psychiatric care (stigma, reputation)?
- Are you ashamed because of the fact that such an illness is present in your family?
- Are you sometimes ashamed because of the patient’s behavior?
- Do you worry about the quality of care in nursing homes or in a psychiatric ward, and whether it would be good enough for the patient?

Check one of the choices below:
- No problem or mild problem
- Moderate problem
- Serious problem
14. Do you sometimes feel that you are not doing enough for the patient? Do you sometimes feel guilty of the patient’s condition or do others blame you for this?

Consider the following to help you rate this question:
- Do you fear that a possible decline in the patient’s condition could be your fault?
- Do you sometimes feel guilty because you need help from others in caring for the patient (e.g. home-care-assistance)?
- If the patient lives in a nursing home:
  - Do you sometimes get the feeling that you did not do enough in order to avoid admission to a nursing home?
- Have others or the patient accused you of this?

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

15. In case the patient is needing nursing care:
Do you sometimes lack the knowledge necessary to nurse the patient properly? Are you under the impression that the patient is often in need of nursing skills that you are unable to provide?

Consider the following to help you rate this question:
- Do you sometimes have to perform duties normally done by a professional nurse, not really knowing whether you are doing them correctly?
- Do you sometimes get the impression that you are not able to assist the patient in personal hygiene properly or sufficiently? (e.g. dental hygiene, bathing, shaving, combing his hair, getting dressed, going to the toilet)
- Are you physically not strong enough for certain nursing duties?
- Do you feel uncomfortable with certain nursing duties?

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
16. Do you sometimes not have enough time for your own household chores because taking care of the patient requires so much of your time?

Consider the following to help you rate this question:
- In the case that your now afflicted partner previously managed the household: Do you occasionally experience difficulties in managing the household?
- Do you sometimes experience difficulties having to shop, cook, clean, and take care of the laundry?

Check one of the choices below:
- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

17. Do you feel that taking care of the patient is sometimes a huge burden or strain on you?

Consider the following to help you rate this question:
- Are you under the impression that you are constantly on your toes?
- Does the patient often disturb your sleep?
- Do you sometimes feel totally exhausted or burned out?
- Do you sometimes have the feeling that you can no longer handle all of it?
- Do you sometimes get the impression that you are no longer able to plan your own life, because the patient has taken over it requiring all your time?

Check one of the choices below:
- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

18. Do you feel sometimes depressed or do you suffer from any physical illness?

Consider the following to help you rate this question:
- Do you suffer from sleeping problems because of the worries you have regarding the patient?
• Do you have the feeling that you are under constant pressure?
• Do you sometimes feel down?
• Do you sometimes feel nervous or anxious?
• Do you have recurring physical complaints?
• Do you sometimes have difficulties dealing with your day-to-day duties because you are too exhausted?
• Do you feel completely "burned out"?

Check one of the choices below:

○ No problem or mild problem
○ Moderate problem
○ Serious problem
○ Not known or insufficient information

19. Are there any other problems?

Consider the following when rating this question:
• Do you face problems or burdens in any other area which have not yet been mentioned?
• Do you need help in this area by a professional or by the psychiatric care system?

If you have any other problems, please write them below:

Other problem 1:

Check one of the choices below:

○ No problem or mild problem
○ Moderate problem
○ Serious problem
○ Not known or insufficient information
Other problem 2:

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

Other problem 3:

Check one of the choices below:

- No problem or mild problem
- Moderate problem
- Serious problem
- Not known or insufficient information

Other problem 4:

Check one of the choices below:

- No problem or mild problem
- Moderate problem
Look over your answers to Questions 1 - 19. Using that information, what would you choose as your 3 top needs at this time?

Top need 1:

Please explain why:

Top need 2:

Please explain why:

Top need 3:

Please explain why:
Thank you

Please provide us with your email address so we can contact you if we have questions about your answers.

Email: 

Please click SUBMIT when you are finished. Once you click it, however, you will not be able to return to this survey.

Submit


Email inquiries about research on the CNA-D to: johannes.wancata@meduniwien.ac.at
Appendix D
Institutional Review Board Approval

To: Cheryl Gies, M.S.N., R.N., C.N.P.
    College of Nursing
From: Roland Skeel, M.D., Chair
       Deepak Malhotra, M.D., Ph.D., Vice Chair
       Gregory Siegel, R.Ph., J.D., Chair Designee
       UT Biomedical Institutional Review Board

Signed: [Signature]
Date: [Date]

Subject: IRB # 106129
Title: Web-based Psychosocial Assessment for Caregivers of Persons with Dementia: A Feasibility Study

On 10/13/2010, the Amendment listed below was reviewed and approved by the Chair and Chair Designee of the University of Toledo (UT) Institutional Review Board (IRB) via the expedited mechanism. The Chair and Chair Designee noted that enrollment continues at this site and that signed and dated Consent/Authorization for Use and Disclosure of Protected Health Information remains required prior to an individual taking part in this research. This action will be reported to the committee at its meeting on 10/21/2010.

Items Available for Review
- IRB Application requesting expedited review of Amendment (UT Reference #7086)
  - Add Ashley Thomasson, Marie Mantleffel and Denise Ware as study personnel
  - Increase enrollment from 20 to 50 (version date 09/10/2010)
  - Revised Consent/Authorization form to increased enrollment (version date 09/10/2010)
  - Add Caregiver Evaluation Questionnaire (version date 10/06/2010)
- RNF and STTI Grant Abstract
- Previous IRB Approved Consent/Authorization Form (version date 05/03/2010)

This Amendment approval is in effect until the expiration date listed below, unless the IRB notifies you otherwise.

Only the most recent [IRB approved] Consent/Authorization form(s) listed above may be used when enrolling participants into this research.

AMENDMENT APPROVAL DATE: 10/13/2010 EXPIRATION DATE: 06/30/2011

Please read the following attachment detailing Principal Investigator responsibilities.

IRB Determination Letter
Appendix E
Caregiver Informed Consent Form

UT IRB # 165129
ICF Version Date: 10/8/2010

College of Nursing
3015 Arlington Ave.
Toledo, Ohio 43614

ADULT RESEARCH SUBJECT INFORMATION AND CONSENT FORM and
AUTHORIZATION FOR USE AND DISCLOSURE OF PROTECTED HEALTH INFORMATION
WEB-BASED PSYCHOSOCIAL ASSESSMENT FOR CAREGIVERS OF PERSONS WITH
DEMENTIA: A FEASIBILITY STUDY

Principal Investigator: Cheryl Gies, MSN, RN, CNP, Assistant Professor, 419-383-5862
Co-Investigators: Victoria Steiner, PhD, Assistant Professor, 419-383-5947
Linda Pierce, PhD, RN, Professor, 419-383-5852
Joan van der Bijl, MSN, CNS-BC, Assistant Professor, 419-383-5801
Diane Salvador, MSN, RN, Assistant Professor, 419-383-5819

PURPOSE (WHY THIS RESEARCH IS BEING DONE)

You are invited to participate in the research project entitled, Web-based Psychosocial Assessment for Caregivers of Persons with Dementia: A Feasibility Study, which is being conducted at the University of Toledo under the direction of Cheryl Gies. The purpose of this study is to examine the experience of using a comprehensive instrument to assess the needs of dementia caregivers, in the Assessment's original face-to-face interview format versus a new self administered web-based format.

You were selected as someone who may want to take part in this study because you are caring for a person with memory problems. Fifty participants will be recruited from the University of Toledo Medical Center's Geriatric Clinic or at educational and support programs sponsored by the Alzheimer's Association.

DESCRIPTION OF THE RESEARCH PROCEDURES AND DURATION OF YOUR INVOLVEMENT

You will be randomized (like flipping a coin) into one of two groups: the web-based group or the interview group.

Web-based Group. Participants in the web-based group will be given the web site address and instructed by the assessor on how to access and complete the Assessment online. Participants will have access to the Assessment for one week and can complete it at their convenience. The web-based Assessment will take approximately one hour.

Interview Group. Participants in the interview group will be able to have the Assessment administered to them by the assessor immediately after entering the study if it is convenient or at another mutually agreed upon place and time. This face-to-face interview Assessment should take approximately one hour.
Regardless of what group you are in, after the Assessment is completed you will be asked to complete a paper/pencil Survey regarding your perception of the assessment experience. Completion of this Survey will take approximately 10 minutes.

After you have completed your participation, the research team will debrief you about the data, theory and research area under study and answer any questions you may have about the research. You will also be mailed a book on caring to thank you for your participation in the study.

RISKS AND DISCOMFORTS YOU MAY EXPERIENCE IF YOU TAKE PART IN THIS RESEARCH

There are minimal risks to participation in this study, including loss of confidentiality. In addition, going through the Assessment and answering the questions about your current caregiving situation might cause you to feel upset or anxious. If so, you may stop at any time.

POSSIBLE BENEFIT TO YOU IF YOU DECIDE TO TAKE PART IN THIS RESEARCH

The only direct benefit to you if you participate in this research may be that you will learn about your caregiving situation and your current needs. The research team will not be able to follow-up with these identified needs, but you can discuss your needs with the Alzheimer’s Association at 1-800-272-3900, or with your health care provider. Others may benefit by learning about the results of this research.

COST TO YOU FOR TAKING PART IN THIS STUDY

There are no costs to you for participating in this study except transportation costs that could be incurred if you chose to meet the assessor at a mutually agreed upon place and time for the face-to-face interview Assessment.

PAYMENT OR OTHER COMPENSATION TO YOU FOR TAKING PART IN THIS RESEARCH

If you decide to take part in this research you will receive a book on caring to thank you for your participation.

CONFIDENTIALITY - (USE AND DISCLOSURE OF YOUR PROTECTED HEALTH INFORMATION)

By agreeing to take part in this research study, you give to The University of Toledo (UT), the Principal Investigator and all personnel associated with this research study your permission to use or disclose health information that can be identified with you that we obtain in connection with this study. We will use this information for the purpose of conducting the research study as described in the research consent/authorization form.

The information that we will use or disclose includes the information that you provide during the assessment of your needs, as well as the data obtained from the Survey about your experience with the Assessment instrument. We may use this information ourselves, or we may disclose or provide access to the information to the funder, the Rehabilitation Nursing Foundation, for study oversight and monitoring, as well as the nurse assessor or data analyst, as part of the research study. Under some
circumstances, the Institutional Review Board and Research and Sponsored Programs of the University of Toledo may review your information for compliance audits. We may also disclose your protected health information when required by law, such as in response to judicial orders.

The University of Toledo is required by law to protect the privacy of your health information, and to use or disclose the information we obtain about you in connection with this research study only as authorized by you in this form. There is a possibility that the information we disclose may be re-disclosed by the persons we give it to, and no longer protected. However, we will encourage any person who receives your information from us to continue to protect and not re-disclose the information.

Your permission for us to use or disclose your protected health information as described in this section is voluntary. However, you will not be allowed to participate in the research study unless you give us your permission to use or disclose your protected health information by signing this document.

You have the right to revoke (cancel) the permission you have given to us to use or disclose your protected health information at any time by giving written notice to Cheryl Gies, 3015 Arlington Avenue, Toledo, Ohio 43614. However, a cancellation will not apply if we have acted with your permission, for example, information that already has been used or disclosed prior to the cancellation. Also, a cancellation will not prevent us from continuing to use and disclose information that was obtained prior to the cancellation as necessary to maintain the integrity of the research study.

Except as noted in the above paragraph, your permission for us to use and disclose your protected health information has no expiration date.

A more complete statement of University of Toledo's Privacy Practices is set forth in its Joint Notice of Privacy Practices. If you have not already received this Notice, a member of the research team will provide this to you. If you have any further questions concerning privacy, you may contact the University of Toledo's Privacy Officer at 419-383-3413.

IN THE EVENT OF A RESEARCH-RELATED INJURY

In the event of injury resulting from your taking part in this study, treatment can be obtained at a health care facility of your choice. You should understand that the costs of such treatment will be your responsibility. Financial compensation is not available through The University of Toledo or The University of Toledo Medical Center.

By signing this form you are not giving up any of your legal rights as a research subject.

VOLUNTARY PARTICIPATION

Taking part in this study is voluntary. You may refuse to participate or discontinue participation at any time without penalty or a loss of benefits to which you are otherwise entitled. If you decide not to participate or to discontinue participation, your decision will not affect your future relations with the University of Toledo, The University of Toledo Medical Center, or the Alzheimer's Association.

NEW FINDINGS

You will be notified of new information that might change your decision to be in this study if any becomes available.
OFFER TO ANSWER QUESTIONS

Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over. If you have questions regarding the research at any time before, during or after the study, you may contact Cheryl Gies at 419-383-5862 or Victoria Steiner at 419-383-5647.

If you have questions beyond those answered by the research team or your rights as a research subject or research-related injuries, please feel free to contact the Chairperson of the University of Toledo Biomedical Institutional Review Board at 419-383-6796.

SIGNATURE SECTION (Please read carefully)

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE IN THIS RESEARCH STUDY. YOUR SIGNATURE INDICATES THAT YOU HAVE READ THE INFORMATION PROVIDED ABOVE, YOU HAVE HAD ALL YOUR QUESTIONS ANSWERED, AND YOU HAVE DECIDED TO TAKE PART IN THIS RESEARCH.

BY SIGNING THIS DOCUMENT YOU AUTHORIZE US TO USE OR DISCLOSE YOUR PROTECTED HEALTH INFORMATION AS DESCRIBED IN THIS FORM.

The date you sign this document to enroll in this study, that is, today’s date, MUST fall between the dates indicated on the approval stamp affixed to the bottom of each page. These dates indicate that this form is valid when you enroll in the study but do not reflect how long you may participate in the study. Each page of this Consent/Authorization Form is stamped to indicate the form’s validity as approved by the UT Biomedical Institutional Review Board (IRB).

Name of Subject (please print) _____________________________________________________________________________________________________________________________________ Signature of Subject or Person Authorized to Consent _____________________________________________________________________________________________________________________________________ Date _____________________________________________________________________________________________________________________________________

Telephone Number: __________________________ Email Address: __________________________

Relationship to the Subject (Healthcare Power of Attorney authority or Legal Guardian) _____________________________________________________________________________________________________________________________________ Time a.m. _____________________________________________________________________________________________________________________________________

Name of Person Obtaining Consent (please print) _____________________________________________________________________________________________________________________________________ Signature of Person Obtaining Consent _____________________________________________________________________________________________________________________________________ Date _____________________________________________________________________________________________________________________________________

Name of Witness to Consent Process (when required by ICH Guidelines) (please print) _____________________________________________________________________________________________________________________________________ Signature of Witness to Consent Process (when required by ICH Guidelines) _____________________________________________________________________________________________________________________________________ Date _____________________________________________________________________________________________________________________________________

YOU WILL BE GIVEN A SIGNED COPY OF THIS FORM TO KEEP.
Appendix F
Male Web-based Educational Module: Financial Issues

Financial Issues When Caring for a Person with AD: A Male Perspective

In these tough economic times, financial issues can be sources of stress for many men. Traditionally, men have held a leadership role in the family as the "provider", responsible for having a job and earning wages that meet the needs of the family. Careful financial planning is an important part of being a good provider.

Adequate finances can become a serious issue for caregivers of persons with Alzheimer’s disease (AD). As one gentleman related, "Right now finances are not an issue, I fear they may be in the future". You too may have already faced unexpected expenses and job issues related to caregiving and now have concerns about what financial problems you may face in the future. AD caregiving is not limited to days or weeks but, is a commitment that is measured in years. The costs of providing care and additional services can become substantial as your loved one’s mental and physical state worsens over time.

This educational module is designed to help you think about some financial issues that men worry about and offer suggestions and resources to help you plan for the future.

Learning Objectives:
Using this module will help you to:

1. Recognize common financial issues for male caregivers.
2. Identify financial resources for short and long term solutions.

Presenter:

Chris Cooper, MSFS, CFP®, EA

Watch the presentation

Listen to the presentation
Presentation Notes:

- Printer-Friendly PDF

Web Links:

- Caregiver Issues:
  - Compassionate Allowances (Social Security Administration)
  - Put a Plan in Place to Deal with Alzheimer’s (Financial Planning Association)
  - When Is It Time to Consider Moving a Family Member with Memory Impairment? (Chris Cooper Company)
- Care Receiver Issues:
  - Financial Matters (Alzheimer’s Association)
  - Help with Medical and Drug Costs (Medicare)
  - Planning for Long Term Care (Financial Planning Association)
  - Representative Payer Program (Social Security Administration)

Other Resources:

- Helping Older Relatives Articulate Their Long-Term Care Wishes (PDF)
- How to Get Paid for Being a Family Caregiver (PDF)
- Men as Caregivers (Prometheus Books)
- More Men Take the Lead Role in Caring for Elderly Parents (PDF)
- Review Financial and Home Resources (PDF)
- Tips for the Working Caregiver (PDF)

References:


Appendix G
Male Web-based Educational Module: Burden and Strain

Male Caregiver Strain or Burden:
Caring for a Loved One with Alzheimer’s Disease

Many men are caring for a loved one with Alzheimer’s Disease (AD). You may be one of these men. You probably already know that over time, persons with AD gradually have more and more trouble thinking and performing everyday activities. At first their “forgetting” is not much of a problem and seems easy to explain, ignore or work around. Most male caregivers adjust to these early memory problems by trying to keep daily life as “normal” as possible. Oftentimes, other relatives or friends bring problems to their attention.

As time goes on, your loved one’s memory and ability to perform self care will decline and you will notice that it takes more of your energy to keep up with day to day responsibilities and caregiving tasks. Most men do not like to ask for help and try to handle caregiving “like a man” by focusing on the tasks and blocking their emotions. Sadly, AD caregiving is not limited to days or weeks; but, becomes more and more complicated as the years go by. The long term effects of this care work puts you at risk for caregiver strain. Helping you find ways to deal with the long term strain or burden of caregiving from a man’s view may be helpful and is the topic of this educational module.

Learning Objectives:
Using this module will help you to:

1. Recognize your own degree of caregiver burden.
2. Recognize when to seek help.
3. Identify where you can receive help.

Presenter:

Robert Hausch, MSW, LISW
AD Care Counselor

[Watch the presentation]

[Listen to the presentation]
DEVELOPING GENDER SPECIFIC WEB-BASED

Presentation Notes:

- Printer-Friendly PDF

Web Links:

- Male Caregiver Obstacles (AARP) - Click > button to listen to presentation
- Geographical Issues of the Male Caregiver (AARP) - Click > button to listen to presentation
- How Are You Doing:
  - Caregiver Burden Scale
  - Stress Assessment: Rate Your Stress Level
  - Caregiver Stress Checklist
- Take Care of Yourself:
  - Caring for Someone With Alzheimer's Disease? Take Care of Yourself Tool
  - Relaxation Techniques (Demential Care Central)
- Dealing with Stress:
  - The Emotional Rollercoaster of Caregiving (Demential Care Central)
  - Strategies for Dealing with Stress (Demential Care Central)

Other Resources:

- Caregiver Depression (PDF)
- Adult Day Centers (PDF)
- Respite Care Guide: Finding What's Best for You (PDF)
- Hospice Care (PDF)

References:


When saying what I said did not mean what I really meant to say

Did you know that most caregivers of persons with Alzheimer’s disease (AD) are women? Personal reasons ranging from love to guilt are why women say they become caregivers. As a woman, you spend most of your day doing care work, dealing with changes in your loved one’s health and behavior and taking on added responsibilities as their ability to function and communicate declines. This is hard work and puts you at risk for strain, depression and health problems.

AD changes your loved one’s ability to communicate. They have difficulty giving a clear message to you and understanding a message from you. This can lead to frustration for both of you. You may feel sad, tense or angry and your loved one may become agitated and even aggressive. This type of behavior can be emotionally and physically difficult for you. Dealing with the communication and related behavior problems of your loved one with AD is difficult and stressful for you.

This module offers tips for dealing with some common communication problems identified when caring for loved ones with AD. Hopefully you will find some of these resources helpful.

Learning Objectives:
Using this module will help you to:

1. Sharpen your communication skills
2. Identify signs of mood changes
3. Know when to use redirection

Presenters:

Cheryl Gies, MSN, RN, CNP
Presentation Notes:

- Printer-Friendly PDF

Helpful Web Links to Improve Communication

1. How to approach
   Click on the link below and then click on the white arrow in the middle of the black screen
   http://www.dementiacarecentral.com/video/approach

2. How to speak to
   Click on the link below and then click on the white arrow in the middle of the black screen
   http://www.dementiacarecentral.com/video/speak
   Click on the link below and then click on the green arrow in the middle of the screen

3. How to have a conversation
   Click on the link below and then click on the white arrow in the middle of the black screen
   http://www.dementiacarecentral.com/video/conversation
   Click on the link below, it will start by itself
   http://www.hcinteractive.com/29

4. How to encourage cooperation
   Click on the link below and then click on the white arrow in the middle of the black screen
   http://www.dementiacarecentral.com/video/motivate

5. How to touch
   Click on the link below and then click on the white arrow in the middle of the black screen
   http://www.dementiacarecentral.com/video/touch

6. How to deal with stress and agitation
   Click on the link below and then click on the green arrow in the middle of the screen
7. How to respond to sudden mood or behavior changes
Click on the link below, it will start by itself
http://www.huinteractive.com/78

Other Resources to Read:

- Dealing with repetition (pdf)
- Ten Tips for communicating with a person with dementia (pdf)
- Tips for effective communication (pdf)
- Unlocking the Silent Prison (pdf)
- Validation and Redirection (pdf)

References:


Appendix I
Female Web-based Educational Module: Time for Self

A Woman's Work: Taking Time for Self

The old phrase "a woman's work is never done" takes on a whole new meaning for you as a woman who is caring for of a loved one with Alzheimer's disease (AD). You are in good company because most caregivers of persons with (AD) are women. As your loved one's memory and ability to perform daily tasks fades, your caregiving responsibilities become more complex. Tasks that used to take minutes may now take hours, leaving little time for you to relax and regain your strength.

Unfortunately, you may think that you can and should handle all the work yourself and you may resist asking for help. Maybe you do not know who to ask or you do not want to "bother" your friends and family. Trying to do everything alone is not in your best interest because eventually, you will feel overwhelmed, lonely and develop health problems. One of the best ways of dealing with the demands of caregiving is to maintain private time.

This module is designed to help you recognize that taking time for yourself everyday is just as important as the wonderful care work you do for your loved one. Your care work will continue to be demanding, but by taking time to take care of yourself, you may experience a feeling of satisfaction because you are emotionally, mentally and physically strong.

Learning Objectives:
Using this module will help you to:
1. Recognize the need to care for yourself
2. Identify three activities that you enjoy
3. Plan one "me" activity each day
4. Consider support resources

Presenter:
Cheryl Gies, MSN, RN, CNP
Watch the presentation
Listen to the presentation
Presentation Notes:

- Printer-Friendly PDF

Web Links to Help You Take Care of Yourself:

1. How are you doing?
   Click on one of these survey links to see how you are doing:

   http://www.alzheimer.ca/english/care/caregivers-howareyoudoing.htm

2. Taking time for yourself
   Click on this link to read “A Guide for Taking Care of Yourself”

3. Relaxation
   a. Meditate
      Click on the link below then click the start arrow at the bottom left of the black video box
      http://www.mayoclinic.com/health/meditation/MM00623

      Click on the link below and read “Finding Pleasure” and “Daily Relaxation”
      http://www.heart.org/HEARTORG/GettingHealthy/StressManagement/
      FourWaystoDealWithStress/Four-Ways-to-Deal-with-Stress_UCM_307996_Article.jsp#relaxation

   b. Yoga
      Click on the link below then click the start arrow at the bottom left of the black video box
      http://www.mayoclinic.com/health/yoga/MM00650

   c. Stress reduction
      Click on each of these links by John Hammarley:
      http://www.americanheart.org/downloadable/heart/flash/flash_content/
      inter/cardiac/flash_videos/Stress120.html

      http://www.americanheart.org/downloadable/heart/flash/flash_content/
      inter/cardiac/flash_videos/Stress118.html

   d. Listen to Music
      Click on this link:
      Music for a Healthy Mind and Body (PDF)

4. Journaling
   Click on this link:
   Reduce Stress by Journaling (PDF)
5. Exercise

Click on this link for the booklet “Be Active Your Way: A Guide for Adults”

Click on this link and scroll down the page to a selection of video offerings of your choice

Click on this link for “Exercising for a Healthy Life”
http://www.nlm.nih.gov/medlineplus/tutorials/exercisingforahealthylife/htm/_yes_50_no_0.htm

6. Nutrition

Click on these links for information on Nutrition

http://www.eatright.org/Public/content.aspx?id=6805


7. Support Services

a. How to choose an Adult Day Care center
Click on this link
http://www.nadsa.org/knowledgebase/details.php?id=5578&printer_friendly=1

Adult Day Care
Click on this link
http://www.nadsa.org/

Adult Day Care
Click on this link
http://www.nadsa.org/assets/library/600_mmidadultdayservices.pdf

b. Helping Hands
Click on this link
http://www.lotsahelpinghands.com/

c. Choosing a home care worker
Click on this link then click on the arrow to listen to the presentation
http://www.aarp.org/relationships/caregiving/info-06-2010/choosing_a_home_care_worker.html

d. Family mediators
Click on this link
http://eldercaremediators.com/
Other Resources to Read:

- Ten Ways to Deal with Caregiver Stress (PDF)
- Elder Mediation (PDF)

References:


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Appendix J
Caregiver Evaluation Questionnaire

IRB #106129
Four page questionnaire: Page 1

Caregiver Evaluation Questionnaire for Web-based Educational Module

Title of the Module is: ________________________________

Section 1 Directions: Please fill in the blank or darken the circle next to your response.

1. My current age is: _______ years.

2. I am:
   ○ Male
   ○ Female

3. My ethnic background is:
   ○ American Indian or Alaska Native
   ○ Asian or Pacific Islander
   ○ Black, not of Hispanic Origin
   ○ Hispanic origin
   ○ White, not of Hispanic Origin
   ○ Other or unknown

4. I have _________ years of education (including college).

5. In general, my health is:
   ○ Poor
   ○ Fair
   ○ Good
   ○ Very Good
   ○ Excellent

6. The person I care for is my ____________________.
Section 2 Directions: Please rate the Educational Module using the numbers 5, 4, 3, 2, or 1.

<table>
<thead>
<tr>
<th>Evaluate the Educational Module</th>
<th>5 Strongly Agree</th>
<th>4 Somewhat Agree</th>
<th>3 Neither Agree nor Disagree</th>
<th>2 Somewhat Disagree</th>
<th>1 Strongly Disagree</th>
</tr>
</thead>
</table>

**Rate the Module Design**

1. The colors in the Module are appealing
2. The print size is easy to read
3. The pictures are appropriate
4. The pictures are interesting
5. The quality of the sound is good
6. It is easy to move through the Module to find information

**Rate the Clarity/Credibility**

1. The speaker's voice is clear
2. The information is concise
3. The information is well organized
4. The authors are clearly stated
5. Contact information is clearly stated

**Rate the Content**

1. The topic is clearly stated
2. This information is useful for a caregiver of a person with dementia
3. This information is new to me
4. The information is interesting
5. The information is easy to understand
6. It will be easy to share this information with others
7. **IF YOU ARE FEMALE:** This content is important to female caregivers
8. **IF YOU ARE MALE:** This content is important to male caregivers

Version date: 10/06/2010

APPROVED BY

UNIVERSITY OF TOLEDO IRB
Section 3 Directions: Please darken the circle “Yes” or “No” indicating your response to the following questions and write in your comments.

1. The information in this Educational Module helped me understand the problem better.
   - No
   - Yes

2. I can use the information from this Module in my caregiving situation to solve a caregiving problem.
   - No
   - Yes

   If Yes, please explain in a few sentences: __________________________________________

3. I think Educational Modules designed specifically for men’s or women’s problems and needs are helpful.
   - No
   - Yes

   Comments: _____________________________________________________________

4. Should anything else be added to this Educational Module?
   - No
   - Yes

   If Yes, please explain in a few sentences: __________________________________

Version date: 10/06/2010
Section 4 Directions: Please use this page to write any additional thoughts or comments that you have about this Web-based Educational Module.

Thank you for reviewing and evaluating this material.
Abstract

Seventy percent of 5.3 million Americans with Alzheimer’s disease (AD) live at home, where family caregivers provide long term, complex care. Evidence in the literature suggests that men and women differ in how they approach and are affected by the experience of caregiving. Caregiver assessment can identify key problems specific to men and women. Cost effective, convenient Web-based Educational Modules (WBEMs) for AD caregivers could support caregivers and provide an efficient resource for healthcare providers in clinical settings. This evidence-based practice project, guided by Friedemann’s Framework and Stetler’s Model, identified gender differences in problems (incongruence) reported by caregivers of persons with AD. Stakeholders are persons with AD, their family caregivers and healthcare providers with Internet access. Gender specific WBEMs were developed to help caregivers cope with these problems. Four male and six female caregivers completed a web-based adaptation of the Carer’s Needs Assessment for Dementia instrument. Assessment results and evidence-based literature were compared to determine key gender differences in caregiving problems. Two male and two female WBEMs were then developed and evaluated for utility, feasibility and functionality by a second group of male (n=6) and female (n=6) caregivers using a Caregiver Evaluation Questionnaire. Both evaluator groups agreed that the WBEMs were well designed with clear, credible, informative content. Suggestions for larger font size and navigation directions will be incorporated in module revisions. WBEMs have potential to re-establish congruence/well-being for caregivers of persons with AD and can be adapted for use by healthcare providers and caregivers of persons with other chronic illnesses.
Keywords: caregivers, caregiver assessment, Alzheimer’s disease, dementia, caregivers, gender differences, caregiver interventions, web-based education, web-based interventions