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Appraisal of caregiving burden, expressed emotion, and psychological distress in families of people with dementia: a systematic review

Susan L. Sprokay

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Pepperdine University

Graduate School of Education and Psychology

APPRAISAL OF CAREGIVING BURDEN, EXPRESSED EMOTION, AND PSYCHOLOGICAL DISTRESS IN FAMILIES OF PEOPLE WITH DEMENTIA: A SYSTEMATIC REVIEW

A clinical dissertation submitted in partial satisfaction
of the requirements for the degree of
Doctor of Psychology

by

Susan L. Sprokay

November, 2015

Shelly Harrell, Ph.D. – Dissertation Chairperson

This clinical dissertation, written by

Susan L. Sprokay

under the guidance of a Faculty Committee and approved by its members, has been submitted to and accepted by the Graduate Faculty in partial fulfillment of the requirements for the degree of

DOCTOR OF PSYCHOLOGY

Doctoral Committee:

Shelly P. Harrell, Ph.D., Chairperson

Robert A. deMayo, Ph.D., ABPP

Karen J. Miller, Ph.D.

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VITA

Susan Sprokay, M.A.

Education

2015	**Doctor of Psychology** Pepperdine University, Los Angeles, California (APA Accredited)
2005	**Master of Arts in Psychology** Pepperdine University, Los Angeles, California (APA Accredited)
1995	**Honours Bachelor of Arts in Psychology** University of Waterloo, Waterloo, Ontario, Canada Specialization in Neuropsychology Minor in Fine Arts Studio

Clinical Experience

October 2015 – Present	***Psychometrist*** **UCLA Geriatric Psychiatry and Longevity Center** Supervisor: Karen Miller, Ph.D. Lead group and individual evidence-based memory enhancing strategies, stress-management techniques and emotional support for individuals experiencing memory loss and/or cognitive impairment and their caregivers. Provide evidence-based, culturally competent neuropsychological services. Provide supervision for students completing externship.
March 2014 – September 2015	***Psychology Intern*** **Wright Institute Los Angeles** Supervisors: Diane Garcia, Ph.D., Peter Wolson, Ph.D., Michele Gomes, Ph.D. Psychodynamically-oriented psychotherapeutic and assessment activities with an outpatient, adult caseload drawn from WILA's Hedda Bolgar Psychotherapy Clinic, individual and group supervision for this caseload, seminars on theory and technique, and administrative and clinical case conferences.
August 2012 – November 2013	***Advanced Neuropsychology Extern*** **UCLA Longevity Center** **Semel Institute for Neuroscience & Human Behavior** Supervisor: Karen Miller, Ph.D. Responsibilities include providing cognitive rehabilitation, group therapy, and didactic presentations to patients with memory disorders and their primary caregivers. Conducting comprehensive intake interviews, administering neuropsychological test batteries, scoring and analysing test results, compiling integrated reports for patients and research participants presenting with suspected cognitive impairment.
July 2008 – August 2011	***Psychotherapist Extern*** **Pepperdine University Community Counseling Center** Supervisors: Aaron Aviera, Ph.D., Shelly Harrell, Ph.D., Joan Rosenberg, Ph.D. Provided psychological services for clients aged 7 – 55 (including individual,

couple, and family therapy) in an outpatient setting catering to clients with diverse backgrounds. In addition to time- limited treatment plans, I was able to commit to longer-term treatments with several clients. Case conceptualization and evidence-based interventions were implemented for symptom presentations including Posttraumatic Stress Disorder, Mixed Anxiety and Depression, Bereavement, Substance Dependence, Generalized Anxiety Disorder, Social Phobia, Narcissistic Personality Disorder.

March 2011
– August 2011

Neuropsychology Extern
Alzheimer’s Disease Research Center, UCLA
Department of Neurology, David Geffen School of Medicine
Supervisor: Ellen Woo, Ph.D.
Responsibilities included conducting comprehensive intake interviews and administration of neuropsychological and psychological (MMPI-2) assessment batteries, scoring and analysing test results, writing integrated reports for patients aged 20 - 90 years with neurological syndromes (e.g., Huntington’s Disease, Vascular Dementia, Bipolar Disorder) and traumatic brain injuries. Administered 12 full neuropsychological assessment batteries for the population specified. Attended weekly didactic seminars regarding case conceptualization and understanding of various neurological diseases.

August 2010
– August 2011

Peer Supervisor
Pepperdine University Community Counseling Center
Supervisor: Aaron Aviera, Ph.D.
Mentored first- and second-year psychology doctoral students in an outpatient setting catering to clients of all ages from diverse backgrounds. Focussed on providing support and guidance in development of clinical skills, case conceptualization, intake report and case note writing. Participated in supervision and training of supervision competencies.

July 2010
– March 2011

Neuropsychology Extern
Aging and Memory Research Clinic Neuropsychology Lab Semel Institute for Neuroscience and Human Behavior, UCLA
Supervisor: Karen Miller, Ph.D.
Responsibilities included conducting full intake interviews and administration of comprehensive neuropsychological assessment batteries, scoring and analysing test results, writing integrated reports for patients (>55 years) with cognitive deficits, specifically memory impairments. Administered 14 full neuropsychological assessment batteries for the population specified. Attended weekly didactic seminars and supervision regarding case conceptualization and understanding of various disorders.

September 2009 –
August 2010

Psychotherapist Extern
Drew Child Development Corporation
Supervisor: Kimberly Hagan, Ph.D.
Provided psychological services (including therapy, psychoeducational testing, and advocacy with school and medical personnel) to individuals and groups of children aged 6 – 12 in elementary school settings in the Compton-Watts area of Los Angeles County. Clients had histories of, or were at high risk for, child abuse. Presenting syndromes including Major Depressive Disorder, Posttraumatic Stress Disorder, Adjustment Disorder, Conduct Disorder, and learning disabilities.

Additional Clinical Experience

June 2012 – October 2013	***Psychological Assistant in Private Practice*** **Neuro-cognitive Assessment & Psychological Services** Supervisors: Karen Miller, Ph.D., Julie Wong, Ph.D. Responsibilities include conducting comprehensive intake interviews, administration of 4-10 hour test batteries that incorporate neuropsychological, academic, and emotional/mood components, scoring and analysing test results, compiling integrated reports for children and adults with possible learning disabilities and/or attention deficit disorders.
June 2012	**Board of Psychology Licensure** Psychological Assistant, CA License PSB 36826
September 2002 – October 2003	***Drug/Alcohol Counselor*** **CLARE Foundation Substance Abuse Prevention Center PATH*Mall*, Hollywood, California** Duties included intake interviews, assessments and referrals for treatment and housing services. The drop-in clients were homeless or living in poverty. I initiated and co-facilitated a weekly support group for those individuals who lived in the 6-month transitional residence onsite.
July 2002 – September 2002	***Intern*** **CLARE Foundation** **Detox/Primary Program, Santa Monica, California** Duties included intake interviews, assessments, counseling, referrals and exit interviews for clients seeking help with drug and alcohol addiction at a 30-day residential facility. Clients aged 18 – 70 came from diverse backgrounds, including individuals who were homeless or transferred from jail.
May 2002	**Certificate in Alcohol & Drug Counseling** University of California, Los Angeles
June 1998 – August 2000	***Volunteer in Partnership*** **Canadian Mental Health Association, Vancouver, B.C.** Responsibilities included spending 3 to 4 hours weekly with a client living with a schizophrenia diagnosis. The goal of the program was to assist the client in developing social skills and in becoming socially active. I planned and participated in many arts and community activities with my client, and much of our time was spent talking and building an interpersonal relationship.
May 1991 – September 1991	***Direct Service Volunteer*** **Canadian Mental Health Association, Oakville, ON, Canada** Duties included assisting in the supervision of up to 12 adult psychiatric outpatients at a daytime drop-in program in activities such as mealtime preparation, games, and weekly field trips.

Research Experience

March 2011 – present	***Doctoral Dissertation*** **Appraisal of Caregiving Burden, Expressed Emotion, and Psychological Distress in Families of People with Dementia: A Systematic Review** Dissertation Chairperson: Shelly P. Harrell, Ph.D. Committee Members: Karen J. Miller, Ph.D., Robert A. deMayo, Ph.D. Unpaid caregivers of people with dementia are faced with a variety of physical,

emotional and social stressors. The aim of this systematic review is to summarize existing evidence regarding subjective burden, expressed emotion and psychological distress related to this category of caregiving and to build a multinational representation of these individuals that will facilitate in identifying areas of supportive intervention.

April 2004 – March 2005	***Project Coordinator*** Pepperdine University, Los Angeles, California Supervisor: Louis J. Cozolino, Ph.D. Managed a team of graduate students involved in research for the book titled *The Neuroscience of Human Relationships: Attachment and the Developing Social Brain*.
January 2004 – April 2004	***Research Assistant*** Pepperdine University, Los Angeles, California Supervisor: Louis J. Cozolino, Ph.D. Assisted with the book titled *The Making of a Therapist.*
January 2003 – August 2003	***Independent Study Project*** Pepperdine University, Los Angeles, California Supervisor: Susan R. Hall, J.D., Ph.D. Title: *An Integrated Treatment for Subthreshold Bulimia Nervosa: A Case Study*

Publications

Cozolino, L. J., & Sprokay, S. L. (2006). Neuroscience and adult learning. *New Directions for Adult and Continuing Education, 110*, 11–19.
Cozolino, L. J., & Sprokay, S. L. (2006). The evolutionary necessity of psychotherapy. *Revista de Psicoterapia, 16*, 5–28.

Teaching Experience

September 2012 – present	***Memory Trainer*** UCLA Longevity Center Teach cognitive strategies and wellness information to middle- aged and older adults from the community to improve and maintain cognition.
September 2004	***Teaching Assistant*** Professor Louis J. Cozolino, Ph.D. Pepperdine University PSY 712 Clinical Neuropsychology Provided tutoring for doctoral level students.
January 2004	***Teaching Assistant*** Pepperdine University PSY 656 Physiological Psychology Professor Louis J. Cozolino, Ph.D. Proctored and graded exams and provided tutoring for master's level students.

Other Experience

August 1995 – August 2001	***Assistant Manager, Support Services*** Scotiabank, Vancouver, B.C. Responsibilities included supervision and development of administrative staff for the Office of the Vice President for BC Southeast region.

Proficiency in the following tests

Achenbach Adult Self-Report
Achenbach Adult Behavior Checklist
American National Adult Reading Test (AMNART)
Auditory Consonant Trigram (ACT)
Beck Anxiety Inventory (BAI)
Beck Depression Inventory – Second Edition (BDI-II)
Beery-Buktenica Developmental Test of Visual-Motor Integration, 6th Edition (Beery VMI) Bender-Gestalt Test of Visual Motor Integration (BGVMT)
Boston Naming Test – Second Edition (BNT-2)
Brief Visuospatial Memory Test –Revised (BVMT-R)
Brown ADD Scales
Buschke Selective Reminding Test
California Verbal Learning Test – Second Edition (CVLT-II)
Child Behavior Checklist
Clinical Dementia Rating (CDR)
Color Trail Making Test (CTT-1&2)
Conner's Continuous Performance Test – Second Edition (CPT-II)
Conners-Wells Adolescent Self-Report Scales - Revised
Controlled Oral Word Association Test (COWAT – FAS/CFL & Animals)
Draw-a-Person
Draw-a-Clock
Finger Tapping Test (FTT)
Functional Abilities Questionnaire (FAQ)
Geriatric Depression Inventory (GDS)
Hamilton Anxiety Inventory (HamA)
Hamilton Depression Scale (HamD)
Hooper Visual Organization Test
Hopkins Verbal Learning Test – Revised (HVLT-R)
Incomplete Sentence Blank
Mini Mental State Exam (MMSE)
Minnesota Multiphasic Personality Inventory – 2 (MMPI-2)
Montreal Cognitive Assessment (MoCA)
Nelson-Denny Reading Test
New York Story Recall Test
Paced Auditory Serial Addition Task (PASAT)
Rey-Osterrieth Complex Figure Test (RCFT)
Rey 15-item Memorization Test & Rey Word Recognition Task Rorschach Inkblot Test
Ruff Test of Nonverbal Fluency
Stroop Test (Kaplan & Golden)
Trail Making Test
Wechsler Adult Intelligence Scale – Third Edition (WAIS- III) Wechsler Adult Intelligence Scale – Fourth Edition (WAIS- IV) Wechsler Intelligence Scale for Children – Fourth Edition (WISC-IV) Wechsler Memory Scale – Third Edition (WMS-III)
Wechsler Memory Scale – Fourth Edition (WMS-IV)
Wechsler Test of Adult Reading (WTAR)
Wisconsin Card Sorting Test (Hand & Computer Administration) Woodcock Johnson – Third Edition Tests of Achievement (WJ III ACH)

ABSTRACT

Unpaid family caregivers of people with dementia are faced with a variety of physical, emotional and social stressors. A systematic review of the literature was compiled to summarize existing evidence regarding subjective burden, expressed emotion and psychological distress related to this category of caregiving and to build a multinational representation of these individuals that will facilitate in identifying areas of supportive intervention. A synthesis of 44 data sets that included 5,249 participants from 20 countries indicated that the majority of caregivers are experiencing depression and high levels of distress related to their caregiving role, and that a small number of caregivers are relying on coping strategies that may add to their distress. Results suggest an ongoing need for medical and psychology practitioners to be aware of appropriate supportive and mental health interventions to improve the quality of life for people with dementia and their family caregivers.

Chapter 1: Introduction

Statement of the Problem and General Aims

One in three older adults in the U.S. dies with dementia (Alzheimer's Association, 2015). Dementia is a neurocognitive disorder characterized by losses in memory, language, executive function, visual spatial skills, attention and mental speed, sometimes with changes to personality. Worldwide, an estimated 35.6 million people are currently living with dementia (World Health Organization and Alzheimer's Disease International [WHO], 2012). This number is projected to reach 115.4 million people by 2050 (WHO, 2012). Further, out of the top 10 causes of death in the U.S., Alzheimer's disease, which accounts for 60-80% of all dementia cases, is the only cause that is not currently either preventable or curable.

Unpaid family caregivers often take on an essential role in the management of people with dementia because of the high level of dependency associated with the condition. The Alzheimer's Association (2015) calculated that approximately 15.7 million people in the United States provide unpaid caregiving for a family member or friend with Alzheimer's disease, dementia, or mental confusion. Caregivers assist their loved ones with instrumental activities of daily living (IADLs) such as shopping, preparing meals, providing transportation, medication management, financial and legal affair management. In addition, as dementia progresses, family caregivers also provide assistance with personal activities of daily living (ADLs) such as bathing, dressing, grooming, feeding, and toileting, and safety issues such as supervision to avoid wandering and getting lost (Alzheimer's Association, 2015). Having family members who are able to provide care allow people with dementia to live at home for longer, rather than needing to move to residential care facilities.

Despite the benefits to the well-being of the care recipient, informal caregiving has been shown to impact families in terms of financial strain, relationship strain, and the physical and mental health of the caregiver (Aguglia et al., 2004; Alzheimer's Association, 2015; Brashares & Catanzaro, 1994; National Alliance for Caregiving & AARP, 2009; United States Congress Senate Special Committee on Aging, 2012). Caregivers of family members with dementia are more vulnerable to experiencing symptoms of depression and anxiety (Anthony-Bergstone, Zarit, & Gatz, 1988; Caserta, Lund, & Wright, 1996; Joling et al., 2010; Joling et al., 2015). The highest psychological distress is reported by caregivers who are over 70 years old, female, and married to the person for whom they provide care (Rinaldi et al., 2005), which is the most typical demographic profile for caregivers of people with dementia (Alzheimer's Association, 2015; Centers for Disease Control and Prevention [CDC], 2009; CDC, 2010). Caregivers of people with dementia report more deterioration in their own physical health related to chronic stress, including increased risk for heart disease, diabetes, kidney disease, and diminished immune system functioning (Alzheimer's Association, 2015; Vitaliano, Zhang, & Scanlan, 2003; Wu et al., 1999). Also, caregiving for family members with dementia often leads to financial burden due to reduction of paid work hours to be at home with the person needing care and additional out-of-pocket health care costs (Aguglia et al., 2004; Alzheimer's Association, 2015).

The ongoing rise in numbers of people with dementia is necessarily paired by an exponential growth in distressed unpaid caregivers. In many cases, higher ratings of distress in caregivers are correlated with lower mental status scores for dementia patients, along with higher reports of agitation, disinhibition, and abusiveness towards the caregiver (Benoit et al., 2005; Hanson & Clarke, 2013; Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993). Further, higher distress in caregivers has been associated with a greater desire to move the dementia patient to an institutionalized care facility and increased costs of inpatient hospitalization, medical visits, and residential care regardless of the patient’s physical health (Benoit et al., 2005; Hinrichsen & Niederehe, 1994; Miller, Rosenheck, & Schneider, 2010). Medical and psychological clinicians may become acquainted with a caregiver as a secondary participant at the dementia patient’s appointment. As the research below will indicate, clinicians play an important role in maintaining the health of the caregiver-care recipient pair when they are able to identify and address caregivers’ needs for intervention.

Prior research has investigated correlations between demographic data and the concepts of subjective caregiver burden, expressed emotion, and/or psychological distress. In addition, prior research has investigated effects of interventions designed to alleviate subjective burden and/or psychological distress, or to reduce levels of expressed emotion in caregivers coping with a loved one who suffers from dementia. The primary aim of the proposed systematic review of the literature is to enhance understanding of this group of caregivers. A systematic review is the investigative method that will be used in this dissertation to locate, appraise and synthesize the best available evidence from previous bodies of research in order to draw a clinical picture of distress and coping behaviours related to the role of being an unpaid caregiver for a loved one with dementia that can be applied to a larger group of caregivers than a single study alone (Boland, Cherry & Dickson, 2013). A systematic review expands on the traditional literature review by using a systematic search strategy and applying pre-specified eligibility criteria in order to eliminate bias. The results, therefore, will provide evidence-based information to clinicians.

Background and Significance

Literature will be reviewed to establish a foundational understanding of the global and U.S. national prevalence of dementia and associated caregiving by unpaid family members. In addition, the proposed literature review will attempt to identify stressors associated with caregiving in general, and caregiving for people with dementia in particular, including an overview of previously published systematic reviews and metaanalyses on caregiver burden for dementia. Finally, previous work will be reviewed to establish background knowledge of the development of caregiver burden instruments, instruments used for measuring depression in caregivers, and the development of coping and expressed emotion concepts and measurements.

Dementia

Dementia is a major neurocognitive disorder characterized by declines in cognitive function paired with substantial impairment in independence for daily activities and, at times, accompanied by behavioural symptoms such as depression, psychosis, agitation, or wandering (American Psychiatric Association, 2013) that result in the necessity of assistance or supervision from caregivers. Prevalence estimates of dementia in the United States population indicate that 13.93% of adults 71 years or older meet criteria for dementia, with the most significant predictors of dementia being older age, fewer years of education, and the DNA presence of 1 or more APOE ε4 alleles (Plassman et al., 2007). The role of caregiver is important to maintaining the well-being and dignity of loved ones suffering from dementia in our communities. Typically, care is provided by family members such as the care recipient's spouse, children, or children-in-law who either live with the care recipient or spend significant time each week providing unpaid care.

Caregiver Burden

The extent to which a caregiver experiences feelings of strain and hardship related to the activities and relationship with the care receiver is referred to as subjective caregiver burden (Novak & Guest, 1989; Zarit, Reever, & Bach-Peterson, 1980).

Family caregivers for people with dementia in particular are more likely to endorse high subjective burden at the earliest stages of cognitive decline, when symptoms first become noticeable and the relationship dynamics begin to alter (Berger et al., 2005; Cheah, Han, Chong, Anthony, & Lim, 2012). As caregivers and their loved ones with a dementia diagnosis adapt to the changes, the level of subjective burden experienced by the caregiver tends to decrease and stabilize until the disease progresses to a high level of severity, at which time the level of subjective caregiver burden is again at its highest (Berger et al., 2005; Cheah et al., 2012). High levels of subjective caregiver burden are also closely associated with the consequence of transferring dementia patients from their home in the community into residential long-term care facilities: a very emotional decision for the caregiver when they often face anger and disappointment from their impaired loved one (Arai, Zarit, Sugiura, & Washio, 2002). While the move to residential care facilities may provide respite for the family caregiver, research findings indicate that, in many cases, levels of subjective burden experienced by caregivers do not tend to decline by a significant amount, as the caregiver continues to be involved emotionally and continues to provide logistical care for their loved one (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Gaugler, Mittelman, Hepburn, & Newcomer, 2010).

Measures studying the factors contributing to subjective burden exist to help clinicians understand how they can give support to caregivers. Zarit, Reever, & Bach-Peterson (1980), as well as Novak and Guest (1989), are among the many investigators who have created reliable instruments for measuring subjective caregiver burden. Zarit's Burden Interview, the most widely used clinical instrument, measures the scope of issues frequently mentioned by caregivers in clinical settings, including caregiver's physical health, psychological well-being, level of financial strain, quality of social life, and relationship with the care recipient. These factors are combined into an overall level of subjective burden score. Novak and Guest's Caregiver Burden Inventory (CBI) measures the impact of caregiving across five dimensions of the carer's sense of burden, and produces an overall level of subjective burden score as well as scores indicating level of burden for each dimension:

- Time-dependence burden. Measures increased time and effort spent towards assisting the care recipient with ADLs and increased vigilance in monitoring care recipient's behaviours.
- Developmental burden. Measures extent to which one's stage of life has been disrupted, such that life is not turning out the way one had expected.
- Physical burden. Measures reported chronic fatigue and increases in physical illnesses or risk for physical illnesses.
- Social burden. Measures feelings of being unappreciated or neglected, as well as conflict with other family members over how to manage the care of their impaired loved one.
- Emotional burden. Measures feelings such as shame, embarrassment, resentfulness, or anger related to the care receiver.

The existing literature suggests that a synthesis of the many existing studies that measure caregiver burden in families of people with dementia will provide a broader view of the impact of caregiver burden on family members across nations, cultures and languages. Further, a synthesis will indicate the prevalence of high or severe levels of burden so that clinicians working with families of dementia patients will be aware of how much importance needs to be placed on educating themselves about appropriate referral resources

Coping and Expressed Emotion

Following the lead of psychiatric research on subjective caregiver burden, researchers in Alzheimer’s disease and other dementias have looked at associations between the subjective experience of caregiver burden and the ways family members cope with and express their emotions related to the care recipient (Cooper, Katona, Orrell, & Livingston, 2008; Fearon, Donaldson, Burns, & Tarrier, 1998; Hinrichsen & Niederehe, 1994; Li & Murray, 2014; Upton & Reed, 2006; Vitaliano et al., 1993). People naturally experience a variety of emotional reactions related to the cognitive decline of a loved one and the associated lifestyle and relationship changes. Some of the ways caregivers cope with their emotions can be conceptualized from a strategic coping response perspective.

In their development of the Ways of Coping questionnaire, Folkman and Lazarus (1988) presented a theory of cognitive and behavioural coping strategies that has been useful for understanding how coping styles mediate the experience and expression of multiple and possibly conflicting emotions that arise in stressful circumstances. Their findings outline 8 forms of coping that can be categorized into predominant categories:

- Emotion-focused strategies. Includes self-control, accepting responsibility, positive reappraisal, and seeking social support.
- Problem-focused strategies. Includes planful problem solving and seeking social support.
- Dysfunctional strategies. Includes ineffective emotion- or problem-focused strategies such as escape-avoidance, distancing, and confrontive coping (i.e., expressing hostility).

Carver, Scheier & Weintraub (1989) built upon the concepts from the Ways of Coping questionnaire to propose a multidimensional view of how people regulate emotions with coping strategies, named the Coping Orientations to Problems Experienced (COPE) inventory. The multiple scales were further categorized into emotion-focussed, problem-focused and dysfunctional strategies as follows (Cooper, Katona, Orrell, & Livingston, 2008). The dysfunctional strategies category includes behavioural disengagement/giving up, denial, self-distraction, self-blame, substance use, and venting negative feelings.

Earlier bodies of work developed the concept of "expressed emotion" to better understand an association that had been observed between higher frequency of symptomatic relapse when patients had gone to live with parents or a spouse upon hospital release versus non-family or sibling living arrangements (Brown, Carstairs, & Topping, 1958). The construct of expressed emotion (EE) was developed based on the analysis of interview data. The Camberwell Family Interview (CFI) is a 4 to 5 hour long, private, semi-structured interview for close family members of patients recently hospitalized predominantly with schizophrenia, as well as cases of depression, epilepsy, mania, and other psychiatric illnesses. Eventually, this measure was shortened to a 1 to 2 hour semi-structured interview (Vaughn & Leff, 1976), with questions eliciting the family member's description of the patient's psychological history, irritability and quarrelling, and clinical symptoms in the 3 months prior to hospitalization. The interviews were audio recorded for subsequent rating of the frequency of comments made on 5 qualitative scales, including (Brown, Birley & Wing, 1972):

- Criticism. Frequency of remarks, based on tone of voice and/or content, that reflect resentment, dislike or disapproval of the patient's behaviours.

- Hostility. Frequency of remarks that reflect rejection and/or criticism of the patient's core personality rather than their behaviours, and frequency that criticism comments occur spontaneously on tangential topics.
- Emotional overinvolvement. Frequency of remarks or actions that reflect unusually marked overprotectiveness, devotion, or self-sacrifice related to the patient's illness, including uncontrolled emotion during the interview, such as crying.
- Dissatisfaction. Frequency of remarks expressing dissatisfaction of family life with the patient in the absence of emotion or resentment.
- Warmth. Frequency of spontaneous remarks, based on tone of voice and/or content, that reflect interest, sympathy, and concern for the patient, or enjoyment of mutual activities.

Analysis of the several hundred interviews revealed significant relationships between the frequency of criticism, hostility, and emotional overinvolvement by the caregiver and rehospitalization of the patient for severe symptoms of schizophrenia within a year of release (Brown, Birley, & Wing, 1972; Brown, Carstairs, & Topping, 1958; Brown, Monck, Carstairs, & Wing, 1962). Dissatisfaction and warmth alone were not significant predictors of relapse and were henceforth disincluded from the concept of "expressed emotion;" however, minimal relapse was noted in the rare cases that family members expressed high levels of warmth in the absence of emotional overinvolvement.

Subsequently, researchers have investigated the role of caregiver expressed emotion in symptom severity of numerous other psychiatric and physical illnesses, such as depression, bipolar disorder, cystic fibrosis, eating disorders, posttraumatic stress disorder, alcohol abuse, personality disorders, agoraphobia, diabetes, asthma, epilepsy, arthritis, heart surgery, rheumatoid arthritis, and obesity (Weardon, Tarrier, Barrowclough, Zastowny, & Rahill, 2000).

The ability to predict the course of these diseases from expressed emotion in the family is inconclusive; however, outcome patterns suggest that patients' social adjustment and subjective caregiver burden may be impacted by level of expressed emotion.

Consistent with patterns from the aforementioned studies, a number of studies on the relationship between dementia and expressed emotion indicate that high levels of criticism are related to more behavioural disturbances, psychotic symptoms and depression in patients, but does not appear to have any impact on cognitive decline or ADLs (Tarrier et al., 2002; Vitaliano et al., 1993; Wagner, Logsdson, Pearson, & Teri, 1997). These studies further indicate that caregivers with high levels of expressed emotion are more likely to experience depressive symptoms themselves. Clinical interventions designed to reduce expressed emotion, particularly criticism, in family members have demonstrated success in reducing symptoms of select psychiatric syndromes in patients (e.g. schizophrenia, eating disorders) on par with established patient-directed interventions (Leff, Kuipers, Berkowitz, & Sturgeon, 1985; Montero et al., 2001; Sepulveda et al., 2010). As such, further exploration of interventions designed to reduce expressed emotion in caregivers for dementia patients may be beneficial to clinicians seeking to alleviate the distress of caregivers.

Coping concepts inherent in self-blame and venting negative feelings are closely aligned, respectively, with the expressed emotion scales of emotional overinvolvement and criticism/hostility. Specifically, research in coping strategies reveals parallels between maladaptive attempts to cope with emotional reactions and expressed emotions such as hostility and emotional overinvolvement. Therefore, despite the paucity of published studies relating expressed emotion to dementia caregivers, incorporating published studies relating maladaptive coping strategies to dementia caregivers will be useful in an investigation of the impact of expressed emotion on subjective caregiver burden.

Psychological distress

Caregivers' distress is typically manifested in symptoms of depression and anxiety that clinicians measure using a wide variety of instruments, including self-report inventories designed to ascertain the severity of the symptoms. Signs that a caregiver may be experiencing depression can include frequent feelings of sadness or hopelessness, diminished interest in previously enjoyed activities, marked change in appetite, marked change in sleep habits, feelings of restlessness or lethargy, loss of energy, feelings of excessive guilt, and difficulty making decisions (APA, 2013). Signs that a caregiver may be experiencing anxiety can include excessive worry, fear of the worst happening, feeling nervous or on edge, unable to relax, easily fatigued, difficulty concentrating, difficulty breathing, heart pounding or racing, feeling hot or flushed, sweating, indigestion, muscle tension, irritability, difficulty sleeping, and feeling lightheaded or shaky (APA, 2013).

Joling et al. (2010) identified 218 spouses of Dutch patients who had received a dementia diagnosis and compared their incidence rates from depression and anxiety to age- and gender-matched comparison spouses. They followed the two groups for a six year period and found that while the two groups did not differ in frequency of anxiety diagnoses, the incidence rates for depression was 1.88% per year in spouses of people with dementia compared with 0.44% per year in spouses of people without dementia. Similarly, in the U.S., Russo, Vitaliano, Brewer, Katon, and Becker (1995) compared 82 spouse caregivers of people with dementia with matched controls and found that 20% of caregivers experienced a major depressive episode after the care recipient was diagnosed with dementia, compared with 7% of noncaregivers.

A systematic review by Schoenmakers, Buntinx, and Delepeliere (2010) found that female caregivers are at higher risk for depression than their male counterparts, spouses are more often depressed than nonspouses, and Caucasian-American caregivers are more likely to become depressed than African-American and Latin-American caregivers. In terms of age differences in factors contributing to depression, older caregivers more often cited fear of dying before their care recipient and the impact of their own physical limitations on the care they are able to provide, whereas younger caregivers were more likely to cite the strain of integrating caregiving with their other responsibilities to jobs, family and friends.

The three- to fourfold greater frequency of depression diagnoses found in caregivers whose loved one has a dementia diagnosis indicates a need for specialized intervention by psychology clinicians. Further analysis and synthesis of existing empirical studies will be helpful in understanding the severity of depressive symptoms experienced by a broader group of these caregivers than can be gleaned from single studies. Awareness of severity of depressive symptoms in this group informs the urgency and nature of interventions required.

Study Rationale and Research Objectives

In recent years, our society has grown in its awareness of caregiver distress in the families of dementia patients. Consequently, there is a growing body of published work about interventions and effects of caregiving on people with loved ones suffering from dementia (Cohen, Colantonio, & Vernich, 2002; Elliott, Burgio, & DeCoster, 2010; Pinquart & Sörensen, 2006; Sanders, Ott, Kelber, & Noonan, 2008; Schultz & Martire, 2004; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007). For most medical and mental health practitioners seeking a general understanding of this diverse population, there are too many studies to identify and consider. To date, there has been a paucity of systematic reviews that provide a focused description of caregivers of people with dementia. An overview of currently available studies will assist practitioners in identifying caregiver-care recipient pairs in need of appropriate referrals and support throughout the course of the care recipient's dementia treatment.

The present systematic review is attempting to ascertain a current clinical representation of unpaid caregivers of people with dementia. In order to construct this clinical picture, the present study aggregates, analyzes and summarises the available evidence on the assessment of subjective caregiver burden, caregiver coping and expressed emotion, and psychological distress in the caregiving experience of people who are unpaid caregivers of people with dementia. The following specific questions are addressed.

Question 1. Based on studies published in academic journals, what are the current demographic characteristics of age, gender, and relationship to patient for caregivers of people with dementia? To answer this question, the systematic review will (a) identify well-established instruments that quantitatively describe caregiver burden, psychological distress, and coping difficulties in unpaid family caregivers of people with dementia; (b) identify published studies that use aforementioned instruments; and (c) systematically organize data from these published studies to describe the demographic characteristics of a broad sample of caregivers.

Question 2. With respect to caregiver burden, what percentage of caregivers endorse low burden, moderate burden, and high burden? This question will be addressed by describing subjective burden trends for caregivers of people with dementia in order to help identify which caregivers are enduring clinically significant levels of burden. Clinically significant cutoff scores will be used to categorize caregivers and describe burden characteristics.

Question 3. What percentage of caregivers endorse minimal depression, moderate depression, and severe depression? This question will be addressed by describing depression trends for caregivers of people with dementia in order to help identify which caregivers are enduring clinically significant levels of depression. Clinically significant cutoff scores for depression will be used to categorize caregivers and describe caregiver depression.

Question 4. What percentage of caregivers demonstrate emotion-related coping strategies that have been associated with exacerbating subjective burden? This question will be addressed by describing expressed emotion trends for caregivers of people with dementia in order to help identify caregivers whose coping includes high expressed emotion.

Chapter 2: Methodology

Review and Analysis Procedures

This chapter presents elements of the research methodology. This will include the following procedures: identification and collection of relevant literature on the assessment of caregiver's subjective burden, expressed emotion, and psychological distress in families of people with Alzheimer's disease and other dementias; clinical review of existing literature; organization of a comprehensive literature table; construction of data tables; and narrative synthesis of data.

Search Applications

Searches to identify relevant literature were conducted utilizing the following electronic databases: Google Scholar, PubMed, PsychINFO, and WorldCat. Additional searching through reference lists and relevant journals were also be performed. Only literature available through the Pepperdine University and University of California, Los Angeles libraries, interlibrary loans, and local public libraries was considered for inclusion. Additional hand searching of reference lists from key articles was also carried out. Journals were searched up to June 2014. Terms will be searched in titles and abstracts of articles with clinical trials. Keywords used for searches were: Alzheimer's disease, dementia, memory disorder, carer, caregiver, caregiving, expressed emotion, burden, psychological distress, stress, anxiety, depression. Only articles published in the English language were reviewed. There may be extant unpublished articles related to this topic that could not be included in the list of reviewed articles.

Measures

The literature analyzed includes studies that utilize various measures of subjective caregiver burden, expressed emotion constructs, and psychological distress. The initial review of the literature yielded studies using multiple measures that were considered for eligibility. Studies with commonly utilized measures of the identified constructs were systematically selected for inclusion.

Caregiver burden. In terms of subjective burden, the initial literature review revealed caregivers were typically assessed using one or more of the following fourteen instruments: Zarit Burden Interview, Caregiver Burden Inventory, Caregiving Appraisal Scale, Caregiver Assessment of Function and Upset, Caregiver Load Scale, Caregiver Reaction Assessment, Caregiver Strain Index, Caregiver Tasks, Caregiver Well-Being Scale, Frustrations of caregiving subscale from the REACH II Quality of Care measure, Modified Caregiver Appraisal Scale, Caregiver Assessment of Functional Dependence, Caregiver Upset measure, Neuropsychiatry Inventory. In order to streamline the procedures, the most frequently occurring instruments used in articles related to dementia were selected for the study.

Coping and expressed emotion. An initial review of the literature revealed a paucity of articles formally measuring expressed emotion in caregivers of people with dementia. In order to attain a wider scope of the concept of expressed emotion in caregivers of people with dementia, results from measures of coping that incorporate the key constructs of criticism, hostility and emotional overinvolvement were considered for inclusion. As such, the following five instruments were identified in the preliminary review: Camberwell Family Interview (CFI), Five Minute Speech Sample (FMSS), Level of Expressed Emotion (LEE), Brief Coping Orientations to Problems Experienced (Brief COPE), and the Dementia Management Strategies Scale (DMSS).

Psychological distress. In terms of psychological distress, the preliminary literature search revealed few studies that included caregiver anxiety data, deeming it difficult to provide a robust description of the sample in terms of anxiety, therefore only studies of caregiver's depressive symptoms were included. The following nine instruments have been identified as having been administered to caregivers in multiple research studies: Beck Depression Inventory (BDI), Beck Depression Inventory II (BDI-II), Brief Symptom Inventory (BSI), Center for Epidemiological Studies Depression Scale (CES-D), General Health Questionnaire-28 (GHS-28), General Health Questionnaire-12 (GHS-12), Hospital Anxiety and Depression Scale (HADS), Symptoms Checklist-90 (SCL-90), and Geriatric Depression Scale (GDS).

Organization of the Literature

In order to organize and analyze the literature that was selected, a table was constructed with the following categories. The results are shown in Appendix A.

- Article. Includes author(s), year of publication, title, source title and page numbers.
- Annotation. Includes summary of main findings.
- Burden Instrument. If relevant, includes name of subjective caregiver burden scale used in the study.
- EE Instrument. If relevant, includes name of expressed emotion construct scale used in the study.
- Distress Instrument. If relevant, includes name of depression scale used in the study.
- Syndrome Studied. Includes description of author's principal focus in researching participants of the study.

Analysis Procedures

Studies including quantitative data measures (i.e., mean, standard deviation, and number of participants) for caregivers of people with dementia were extracted from the studies. Only papers with published quantitative data measures were considered for inclusion. The following outcome variables were eligible for inclusion: caregiver burden, expressed emotion (criticism, hostility, emotional overinvolvement), psychological distress (depression). Whenever two or more sets of repeated measures were found in an article, only the baseline (pre-intervention) data was used for the purposes of this review. Data from three sets of studies (Vitaliano, Becker, Russo, Magana-Amato, & Maiuro, 1988-89; Vitaliano et al., 1993), (Liew et al., 2010; Seng et al., 2010; Tan, Yap, Ng, & Luo, 2013; Yap, Luo, Ng, Chionh, & Goh, 2010), (Anthony-Bergstone, Zarit, & Gatz, 1988; Zarit, Anthony, & Boutselis, 1987) included measures of the same population; as such, only data from Vitaliano et al. (1993), Liew et al. (2010), and Anthony-Bergstone et al. (1988) were used for the purposes of this review. In order to determine cutoff scores for clinical significance, literature reviews were performed on the instruments included to find commonly accepted norms.

Construction of Data Tables

In order to clearly present the data that was extracted, a series of tables were constructed for each of the following subtopics:

- Studies that measure caregiver burden.
- Studies that measure caregivers' level of expressed emotion.
- Studies that measure caregivers' psychological distress.

Within each table, data was organized into the following categories:

A. Author(s), year of publication, and country where study was performed.
B. Relationship to patient.
C. Sample size and mean age of patients.
D. Sample size, gender, and mean age of caregiver.
E. Name of instrument used.

F. Mean and standard deviation of pertinent scales from the instrument.

Restrictions Applied to Data for Study Inclusion

In order to provide a robust description of the dementia caregiver sample to be included in this review, parameters were applied to the collected data sets. First, the following restrictions were applied to the subjective caregiver burden data: only studies with a minimum sample size of 50 were included; only studies published in the past 15 years were included (1999 – 2014); and with respect to the ZBI, only studies using the 22-item version were included. Second, the search revealed a paucity of recently published studies of expressed emotion in caregivers of people with dementia. As such, fewer restrictions were applied on the data analyzed in this dimension. The following restrictions were applied to the expressed emotion data: a minimum sample size of 30 was required for inclusion; only studies published in the past 20 years were included (1994 – 2014). Finally, the following restrictions were applied to the psychological distress data: the search revealed few studies that included caregiver anxiety data, deeming it difficult to provide a robust description of the sample in terms of anxiety, therefore only studies of caregiver's depressive symptoms were included; only studies with a minimum sample size of 50 were included; only studies published in the past 15 years (1999 – 2014) were included.

Chapter 3: Results

The results of this systematic review present a current clinical representation of unpaid caregivers of people with dementia. Electronic databases were consulted to identify instruments used in scientific research that assess caregivers' subjective burden, coping and expressed emotion, and depression. This section first describes the relevant instruments, including normative scores that were used to analyze findings. Next, ethnicity and socioeconomic markers found in the studies are described. The following sections provide characteristics of the participant caregivers. Lastly, mean scores for each included study were compared to the normative scores to determine the severity of subjective burden, trends in use of expressed emotion in coping as well as correlations found between coping styles and lower severity of burden or distress, and the severity of depression in unpaid caregivers of people with dementia.

Measurement Instruments

The systematic review yielded studies using the following measures of subjective caregiver burden, expressed emotion, and psychological distress.

Caregiver burden.

Zarit Burden Interview. As previously mentioned, the ZBI is a self-report measure of caregiver's physical health, psychological well-being, level of financial strain, quality of social life, and relationship with the care recipient. The revised version consists of 22 items that are rated on a Likert scale (0 = never to 4 = nearly always). Shorter versions of the ZBI have been created for ease of use by clinicians, including a 12-item and a 7-item version, both with excellent correlations to the long version (Bédard et al., 2001). There is no universally defined cutoff point in the ZBI for high or low subjective burden. As such, reference values for ZBI scores are based on Hébert, Bravo & Préville's (2000) study, indicating high subjective burden

(50th to 74th percentile) with score of 18.5 to 32.9 on the 22-item version and severe subjective burden (75th percentile and above) with a score of 33 or higher on the 22-item version.

Caregiver Burden Inventory. As previously mentioned, the CBI is a self-report measure of the impact of subjective burden on caregivers. It consists of 24 items organized into 5 subscales representing discrete dimensions of subjective burden: time-dependence, developmental, physical, social, and emotional. Items are rated on a Likert scale (0 = never to 4 = nearly always). There is no universally defined cutoff point in the CBI for high or low burden. As such, for the purposes of this study, reference values for CBI scores are based on Rinaldi et al.'s (2005) study, indicating high subjective burden with scores of 49.37 ± 12.1 and low subjective burden with scores of 20.79 ± 11.2.

Expressed emotion.

Camberwell Family Interview. The CFI is a standardized, audio recorded interview that is later reviewed by trained raters who record the frequency of comments made reflecting criticism of the patient, hostility towards the patient, and emotional overinvolvement with the patient. Administration of the interview typically takes 1 to 2 hours, and scoring typically takes 2 to 3 hours. Leff & Vaughn's (1985) classification standards are used to identify high expressed emotion scores that are significantly predictive of relapse in patients with schizophrenia. Specifically, an interview is classified as high expressed emotion if it includes 6 or more critical comments, and/or 3 or more indications of emotional overinvolvement, and/or one or more hostile remarks. However, Butzlaff & Hooley's (1998) study of expressed emotion in families of depressed patients indicated a clinically significant relapse when critical comments cutoff was 3 or more.

Five Minute Speech Sample. The FMSS is a standardized, audio recorded interview that is later reviewed by trained raters. Administration of the interview typically takes 5 minutes, and scoring typically takes 20 minutes. Interviews are rated as high in expressed emotion with the presence of at least one comment reflecting criticism of the patient, or at least one negative opening statement about the patient, or a negative relationship rating. High expressed emotion is also rated when the interviewee demonstrates overprotectiveness of the patient or cries during the interview. Low expressed emotion is determined by the absence of high expressed emotion (Vitaliano et al., 1988-89).

Level of Expressed Emotion. The LEE is a self-report measure of expressed emotion in caregivers. It consists of 60 items organized into 4 domains, each containing 15 items: intrusiveness, emotional response, negative attitude towards the illness, and tolerance towards and expectations of the patient. Items have true/false response options and each item is scored 1 point if the response indicates high expressed emotion. There is no universally defined cutoff point in the LEE for high or low expressed emotion (Van Humbeeck, Van Audenhove, De Hert, Pieters, & Storms, 2002). As such, based on results from a longitudinal study of 43 patients with schizophrenia by the developers of the LEE (Cole & Kazarian, 1993), mean scores of patients rehospitalized within 2 years were used as a general guideline for identifying high EE (LEE = 20.7) and mean scores of patients not rehospitalized after 2 years were used as a general guideline for indentifying low EE (LEE = 11.5).

Brief Coping Orientations to Problems Experienced. The Brief COPE is a self-report measure of how people respond to stressful events in their lives. It consists of 28 items organized into 14 subscales, each subscale comprised of 2 or more pairs of coping responses. This questionnaire does not provide an EE index, as it was not originally designed to be an EE measure. It does, however, include subscales pertaining to the current study: venting (2 items) with features akin to criticism, and self-blame (2-items) with features akin to emotional overinvolvement. Another notable scale measures active coping: making efforts to improve the situation for oneself and one's care recipient. Items are rated on a Likert scale (1 = I usually don't do this at all to 4 = I usually do this a lot). There are no published norms or guidelines for cutoff criteria for the Brief COPE (Meyer, 2001).

Dementia Management Strategies Scale. The DMSS is a self-report measure that consists of 28 items organized into 6 subscales. This questionnaire does not provide an EE index, as it was not originally designed to be an EE measure. It does, however, include a criticism scale that is pertinent to the current study with 11 items that measure efforts to manage the care recipient by yelling, criticizing, threatening, and related behaviours. The other two scales are encouragement (praising or engaging the care recipient in discussing his or her feelings) and active management (efforts to safeguard, stimulate, modify the environment, and draw attention away from upset feelings). Participants are asked to indicate the frequency with which they have used the listed behaviours in the past month on a Likert scale (1 = never to 5 = most of the time). There are no published norms or guidelines for cutoff criteria for the DMSS.

Psychological distress.

Beck Depression Inventory. The BDI is a self-report measure that consists of 21 items assessing intensity of clinical depression consistent with DSM-III criteria and the BDI-II is consistent with the DSM-IV criteria. Papers included in the present study utilized the BDI. Items are rated on a Likert scale (0 = minimal to 3 = severe). When the BDI scores are summed, 10-18 indicates mild depression, 19-29 indicates moderate depression, and 30-63 indicates severe depression (Beck, Steer, & Garbin, 1988).

Brief Symptom Inventory. The BSI is a self-report measure abbreviated from the Symptom Checklist-90 that consists of 53 items organized into 9 subscales. The subscale pertinent to the current study is the Depression subscale, comprised of 6 items. Items are rated on a Likert scale (0 = not at all to 4 = extremely). In the three studies found that established BSI norms for elderly community samples (De Leo, Frisone, Rozzini, & Trabucchi, 1993; Hale, Cochran & Hedgepeth, 1984; Petkus et al., 2010), the means for the six items on the Depression subscale ranged from 0.43 to 0.70. For the purposes of this study, the normative scores from De Leo et al. (1993) will be utilized because his Italian sample most closely matches those included in the present analysis. The mean Depression subscale score for males was 0.41 (*SD* = 0.53) and for females the mean was 0.70 (*SD* = 0.69). The total sample mean Depression subscale score was 0.60 (*SD* = 0.65). The BSI-18 procedural manual suggests a t-score of 63 as a cutoff to indicate significant distress (Derogatis, 1993). As such, clinically significant levels of depression will be indicated by 1.33 standard deviations above the mean (i.e., male score of 1.11, female score of 1.62, total score of 1.46).

Center for Epidemiological Studies Depression Scale. The CES-D is a self-report measure that consists of 20 items intended for use in the general population to assess existing level of depressive symptomatology in the past 7 days. Items are rated on a Likert scale (0 = rarely to 3 = most or all of the time). Lewinsohn, Seeley, Roberts, & Allen (1997) established norms for older adults aged 50+ with a mean of 8.33 (*SD* = 6.84). Lyness et al. (1997) established optimum cutoff scores for recognizing major depressive disorder in older patient samples as 21. As such, for the purposes of the present study, mild or moderate depression will be indicated by 1 standard deviation above the mean (i.e., score of 15.17 to 20) and moderate to severe depression will be indicated by a score of 21 or greater.

Hospital Anxiety and Depression Scale. The HADS is a self-report measure that consists of 14 items with subscales for anxiety and depression comprising 7 items each. The subscale pertinent to the current study is the Depression subscale. Items are rated on a Likert scale (0 = not at all to 3 = definitely/most of the time). When Depression subscale scores are summed, 0-7 indicates normal mood, 8-10 indicates borderline abnormal mood, and 11-21 indicates abnormal mood (Zigmond & Snaith, 1983). Crawford, Henry, Crombie, & Taylor (2001) administered the HADS to a large sample of the general population (*n* = 1792) and found the mean Depression subscale score to be 3.68 (*SD* = 3.07).

Geriatric Depression Scale. The GDS is a self-report measure that consists of 30 items (Long Form) or 15 items (Short Form) intended for use in the older population to assess intensity of depressive symptoms. Items are responded with forced choice (yes or no) in reference to how the participant felt over the last week. When the GDS scores are summed using the Short Form, 0-5 indicates normal mood, 6-10 suggests depression, 11-15 is almost always depression (Brink et al., 1982).

Identification of Published Studies

In order to investigate how unpaid caregivers of people with dementia are assessed for subjective caregiver burden, expressed emotion and psychological distress, a comprehensive literature review was performed (see Figure 1). Of the 53 full-text papers assessed for review, 31 fit the restriction criteria mentioned above. Of the 31 papers included in the present review, 9 contained data that was useable in both subjective caregiver burden and psychological distress analyses (Aguglia et al., 2004; Cohen, Colantonio, & Vernich, 2002; Garcia-Alberca et al., 2014; Miller, Rosenheck & Schneider, 2010; Papastavrou et al., 2007; Papastavrou, Charalambous, Tsangari, & Karayiannis, 2012; Rinaldi et al., 2005; Tremont et al., 2013; Zanetti, Geroldi, Frisoni, Bianchetti, & Trabucchi, 1999). One paper contained data that was useable in subjective caregiver burden, psychological distress and expressed emotion analyses (Cooper, Owens, Katona, & Livingston, 2008). One paper contained 2 discrete instruments used to measure expressed emotion with the same population (Lim, Griva, Goh, Chionh, & Yap, 2011) in addition to data useable in the subjective caregiver burden analysis. As such, a total of 44 data sets were analyzed.

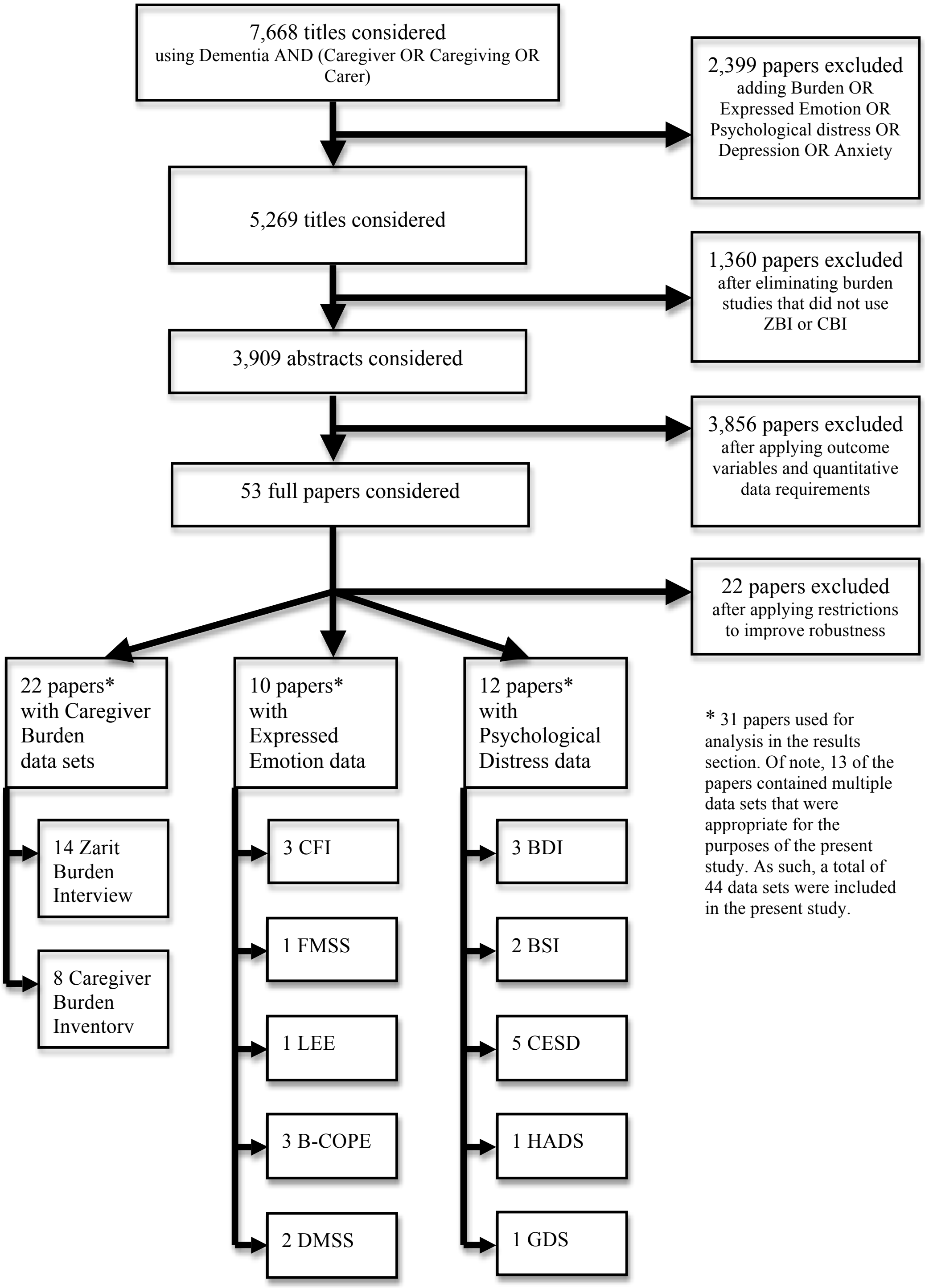
Ethnicity and Socioeconomic Status

Of the 53 full-text papers assessed for review, 13 of the studies (24.5%) reported the ethnicity of the participants. Additionally, eleven studies (20.7%) specified a language other than English used to administer the instruments. In sum, a total of 24 studies (45.3%) included descriptors of either ethnicity or non-English native language of the participant caregivers. In addition, two studies (3.8%) reported the religious affiliation of participants.

Few studies reported socioeconomic status of the participants, with only 7 of the 53 studies (13.2%) using it as a descriptor.

Caregiver burden

In twenty-two studies, subjective burden in unpaid caregivers of people with dementia was rated from the ZBI or the CBI. The instruments were administered by a variety of organizations across multiple countries in their respective languages. Studies were published between 1999 and 2012. Samples were taken from relatives, family members, and spouses of people with Alzheimer's disease (AD), early stage AD, dementia, late onset dementia, mild dementia, cognitive impairment. Patients were residing at home or in an institution. The results are shown in Table 1.



* 31 papers used for analysis in the results section. Of note, 13 of the papers contained multiple data sets that were appropriate for the purposes of the present study. As such, a total of 44 data sets were included in the present study.

Figure 1. Flowchart of study selection process.

Table 1

Studies that have Measured Caregiver Burden Using the Zarit Burden Interview (ZBI) or the Caregiver Burden Inventory (CBI)

Study description (Author/Year/Country)	Sample	Patient		Carer				Measure	Mean (SD)
		N	Age Mean (SD)	N	Fem	Male	Age Mean (SD)		
Aguglia et al. (2004) Italy	AD female relative	236	-	156	156	0	61.1 (SD 13.1)	CBI	26.9 (5.1)
	AD male relative			75	0	75	64.7 (SD 13.6)	CBI	23.8 (4.3)
Akpinar, Küçükgüçclü, Yener (2011) Turkey	AD female relative	192	75.83 (SD 8.91)	120	120	0	54.86 (SD 10.86)	CBI**	54.63 (21.5)
	AD male relative		74.26 (SD 8.27)	72	0	72	57.93 (SD 14.06)	CBI**	44.63 (22.39)
Arai, Matsumoto, Ikeda & Arai (2007) Japan	Late Onset Dementia relative	54	-	54	44	10	Median 70	ZBI	18.0 (range 11-34)
Benoit et al. (2005) France	AD relative living in institution	54	77.2	54	-	-	-	ZBI*	≈27.39 extrapolated from figure
	AD relative living at home	428		428	-	-	-	ZBI*	≈22.2 extrapolated from figure
Cheah et al. (2012) Singapore	Cognitive impairment relative	130		130	93	37	53.9 (SD 13)	ZBI*	18.9 (16.5)
Cohen, Colantonio, Vernich (2002) Canada	Dementia relative	-	84.4	285	-	-	64	ZBI	11.87(12.29)
Cooper, Owens, Katona & Livingston (2008) United Kingdom	AD relative	83	82.2	83	52	31	64.2 (SD 15.4)	ZBI*	18.8 (12.1)
Garcia-Alberca et al. (2014) Spain	AD relative	80	77.34 (SD 5.74)	80	62	18	62.15 (SD 10.37)	CBI*	32.71 (11.35)
Hébert, Bravo & Préville (2000) Canada	Dementia relative community-dwelling	327	-	327	259	68	61.7 (SD 13.4)	ZBI*	22.4 (16.2)

(continued)

Study description (Author/Year/Country)	Sample	Patient		Carer				Measure	Mean (SD)
		N	Age Mean (SD)	N	Fem	Male	Age Mean (SD)		
Hirakawa et al. (2008) Japan	Family of mild dementia	725	81.7 (SD 8.04)	725	570	155	64.2 (SD 12.54)	ZBI*	29.6 (16.36)
	Family of severe dementia	261	82.7 (SD 8.26)	261	198	63	64.49 (SD 11.41)	ZBI**	35.51 (16.76)
Lim et al. (2011) Singapore	Dementia Family member	109	78 (SD 8.9)	109	77	32	49 (SD 10.8)	ZBI**	34.2 (13.9)
McLennon, Habermann & Rice (2011) U.S.A.	Dementia Co-resident spouse	84	79.3 (SD 8.9)	84	50	34	73.3 (SD 10.5)	ZBI*	30.73 (14.9)
Miller, Rosenheck & Schneider (2010) U.S.A.	AD relative	421	77.9 (SD 7.5)	410	320	90	63 (SD 15.5)	ZBI**	34.42 (15.99)
Papastavrou et al. (2007) Cyprus	Probable AD relative living at home	130	74.5	130	-	-	56.8 (SD 13.38)	ZBI**	50.29 (17.35)
Papastavrou et al. (2012) Cyprus	Dementia family member	172	-	172	132	40	56.8 (SD 13.3)	ZBI**	49.1 (17.1)
Raccichini et al. (2009) Italy	AD family member	208	-	208	144	64	77.93 (SD 6.15)	CBI	25.47 (17.68)
Rinaldi et al. (2005) Italy	Dementia relative	419	75.8 (SD 7.7)	419	302	117	58.2 (SD 14.1)	CBI*	32.5 (18)
Schneider, Murray, Banerjee & Mann (1999) European Union (14 countries)	AD co-resident spouse	280	73	280	162	118	71 yrs	ZBI**	36
Simonelli et al. (2007) Italy	AD spouse	-	-	100	67	33	71.71 (SD 5.716)	CBI	31.59 (19.515)
Tremont et al. (2013) U.S.A.	Dementia family	250	78.06 (SD 10.06)	250	195	55	62.72 (SD 12.99)	ZBI**	38.18 (14.12)
Zanetti et al. (1999) Italy	Dementia relative	111	74.4 (SD 8.4)	111	73	38	54.6 (SD 13.1)	CBI	20.4 (16.9)
Zucchella et al. (2012) Italy	Early stage AD relative	126	76.13 (SD 6.19)	126	96	30	56.11 (SD 12.37)	CBI	19.95 (16)

Note. ZBI low burden indicated by scores below 18.5, high burden indicated by score of 18.5 to 32.9 and severe burden indicated by a score of 33 or higher. CBI low burden indicated by scores below 32, moderate burden indicated by scores of 32 to 37.26 and high burden indicated by scores of 37.27 or higher.

* Results indicate high subjective burden on ZBI and moderate subjective burden on CBI

** Results indicate severe subjective burden on ZBI and high subjective burden on CBI

In seven of the studies, the mean subjective burden score was below the cutoff. Five of these studies used the CBI and were conducted in Italy and published between 1999 and 2012 (Aguglia et al., 2004; Raccichini, Castellani, Civerchi, Fioravanti, & Scarpino, 2009; Simonelli et al., 2008; Zanetti et al., 1999; Zucchella, Bartolo, Pasotti, Chiapella, & Sinforiani, 2012). The individual studies had samples ranging from 75 to 208 caregivers, with a combined total of 776 participants. Mean ages of caregivers ranged from 54.6 to 77.93 years; 536 of the participants were female and 240 were male. The CBI mean scores for this group ranged from 19.95 to 31.59. The remaining 2 studies with results below the cutoff used the ZBI and were conducted in Japan and Canada and published in 2007 and 2002, respectively (Arai, Matsumoto, Ikeda, & Arai, 2007; Cohen et al., 2002). The individual studies had samples ranging from 54 to 285, with a combined total of 339 participants. Ages of caregivers ranged from a median of 70 years to a mean of 64 years. The Japanese study included 44 female and 10 male caregivers; gender of caregivers was not specified in the Canadian study. The ZBI scores for the Japanese study ranged from 11 – 34, with a median of 18; the ZBI mean score for the Canadian study was 11.87.

In eight of the studies, the mean subjective burden score was in the moderate-high range. Two of these studies used the CBI and were conducted in Spain and Italy and published in 2014 and 2005, respectively (Garcia-Alberca et al., 2014; Rinaldi et al., 2005). The individual studies had samples ranging from 80 to 419 caregivers, with a combined total of 499 participants. Mean ages of caregivers ranged from 58.2 to 62.15 years; 364 of the participants were female and 135 were male. The CBI mean scores for this group ranged from 32.5 to 32.71. The remaining 6 studies with results in the moderate-high range used the ZBI and were conducted in multiple countries, including Canada, France, Singapore, United Kingdom, and the U.S.A. and published between 2000 and 2012 (Benoit et al., 2005; Cheah et al., 2012; Cooper, Owens et al., 2008;

Hébert, Bravo, & Préville, 2000; Hirakawa, Kuzuya, Enoki, Hasegawa, & Iguch, 2008; McLennon, Habermann, & Rice, 2011). Of note, one of these studies (Hirakawa et al., 2008) sorted the participants into two groups based on severity of their family members' dementia; only the group associated with mild dementia had subjective burden scores in the moderate-high range and is described here. The caregiver group associated with severe dementia will be described in the high-severe range section. The individual studies had samples ranging from 54 to 725 caregivers, with a combined total of 1,831 participants. The France study did not specify age or gender of the 482 caregivers in their study; however, for the remaining studies, mean ages of caregivers ranged from 53.9 to 73.3 years and 1,024 of the participants were female and 325 were male. The ZBI mean scores for this group ranged from 18.8 to 30.73.

In eight of the studies, the mean subjective burden score was in the high-severe range. One of these studies used the CBI and was conducted in Turkey and published in 2011 (Akpinar, Küçükgüçclü, & Yener, 2011). The study sorted the participants into 2 groups based on gender of caregiver and included 120 females and 72 males; mean ages of caregivers were 54.86 and 57.93 years, respectively, with respective CBI mean scores of 54.53 and 44.63. The remaining 7 studies with results in the high-severe range used the ZBI and were conducted in multiple countries, including Austria, Belgium, Cyprus, Denmark, Finland, Greece, Ireland, Italy, Japan, Luxembourg, Netherlands, Portugal, Singapore, Spain, Sweden, United Kingdom, and the U.S.A. and published between 1999 and 2013 (Hirakawa et al., 2008; Lim et al., 2011; Miller, Rosenheck, & Schneider, 2010; Papastavrou et al., 2007; Papastavrou et al., 2012; Schneider, Murray, Banerjee, & Mann, 1999; Tremont et al., 2013). As previously noted, in the Hirakawa et al. (2008) study, only the caregiver group associated with severe dementia is described in this section. The individual studies had samples ranging from 109 to 410 caregivers, with a combined total of 1,612 participants. The mean ages of caregivers ranged from 49 to 71 years. One study did not specify gender (Papastavrou et al., 2007); for the remainder of studies, 73% of the participants were female and 27% were male. The ZBI mean scores for this group ranged from 34.2 to 50.29.

In sum, in 23 studies with 5,249 caregiver participants, 7 studies (1,115 participants – 21.3%) showed a mean score below the clinical cutoff for subjective burden, 8 studies (2,330 participants – 44.4%) showed a mean score in the moderate to high subjective burden range, and 8 studies (1,802 participants – 34.3%) showed a mean score in the high-severe subjective burden range. The chart in Figure 2 depicts a comparison of caregiver burden results.

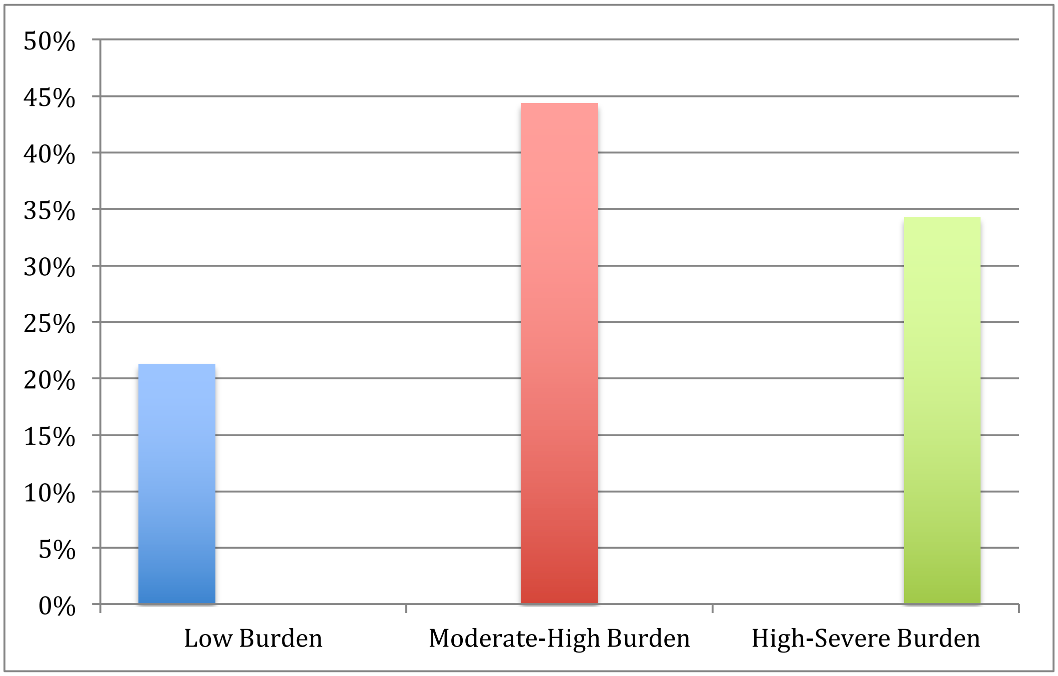


Figure 2. Comparison of caregiver burden results.

Coping and Expressed Emotion

In eight studies, expressed emotion in unpaid caregivers of people with dementia was described by results using the Camberwell Family Interview (CFI), Five-Minute Speech Sample (FMSS), subscales of the Brief Coping Orientations to Problems Experienced (Brief COPE), and/or a subscale of the Dementia Management Strategies Scale (DMSS). The instruments were administered by a variety of organizations in Singapore, Taiwan, United Kingdom, and the U.S.A. using English or Chinese versions. Studies were conducted between 1998 and 2013. Samples were taken from relatives, family members, and spouses of people with possible or probable Alzheimer's disease (AD), dementia, and mild cognitive impairment (MCI). One study (Lim et al., 2011) measured aspects of expressed emotion using two discrete instruments with the same sample group. The individual studies had samples ranging from 36 to 201, with a combined total of 818 participants; 569 of the participants were female and 249 were male. Mean age for caregivers in 6 of the studies ranged from 49 to 74.04 years; one study (McCurry, Vitiello, Gibbons, Logsdon, & Teri, 2006) indicated participant age as a range (21–87 years). The results are shown in Table 2.

The CFI was used to measure caregivers EE in two studies (Fearon, Donaldson, Burns, & Tarrier, 1998; Tarrier et al., 2002). Sample sizes ranged from 99 to 100, with a combined total of 199 participants. Mean age of caregivers in both studies was 63 years; 113 of the participants were female and 86 were male. Results using the CFI showed predominantly low EE in unpaid caregivers of people with dementia. Specifically, criticism mean scores ranged from 2.87 to 5.11, emotional overinvolvement mean scores ranged from 1.16 to 1.51, and hostility mean scores ranged from 0.36 to 0.77. These results indicate an overall low level of EE.

In terms of the FMSS, one study reported 44% of the unpaid caregivers were rated as high EE and the remaining 56% of the caregivers were below cutoff for high EE (Hanson & Clarke, 2013). There were a total of 46 participants. The mean age of caregivers was 74.04 years; 33 of the participants were female and 13 were male.

Results from the one study using the LEE showed overall EE in unpaid caregivers of people with dementia exceeded the low score cutoff, with a mean total score of 13.63 mean moderate level of EE for this caregiver sample. There were a total of 65 participants. The mean age of caregivers was 59.7 years; 47 of the participants were female and 18 were male.

In terms of the Brief COPE, two studies measured venting negative feelings and self-blame as strategies for coping with caregiver stressors (Lim et al., 2011; Ott, Sanders, & Kelber, 2007). Results from these samples showed minimal use of venting with mean scores ranging from 2.17 to 3.2 and minimal use of self-blame with mean scores ranging from 2.28 to 2.8. These results indicate an overall low level of EE for this caregiver sample. Sample sizes ranged from 109 to 201, with a combined total of 310 participants. Mean ages of caregivers ranged from 49 to 64.07 years; 239 of the participants were female and 71 were male.

Three studies used the DMSS to measure criticism, a key factor in determining level of EE (Hinrichsen & Niederehe, 1994; Lim et al., 2011; McCurry et al., 2006). Results from these samples showed mean scores ranging from 23.1 to 25.74, indicating moderate levels of criticism. The 109 participants in the Lim et al. study are previously described by their results on the Brief COPE measure. In both the DMSS and Brief COPE, these participants reported similarly low levels of criticism and emotional overinvolvement. As such, only the results from the Brief COPE will be included in the results section. Of the remaining two DMSS studies, sample sizes ranged from 46 to 152, with a combined total of 198 participants; 137 of the participants were female and 61 were male. The mean age in two of the studies ranged from 49 to 59.6 years. The third study reported caregivers' range of ages from 21 to 87 years.

Table 2

Studies that have measured caregivers' level of expressed emotion with the Camberwell Family Interview (CFI), Five-Minute Speech Sample (FMSS), Brief Coping Orientations to Problems Experienced (Brief COPE), and Dementia Management Strategies Scale (DMSS)

Study description (Author/Year/Country)	Sample	Patient		Carer				Measure	Criticism/ Venting Mean (SD)	Hostility Mean (SD)	EOI/Self-blame Mean (SD)	EE Total Mean (SD)
		N	Age	N	Fem	Male	Age					
Fearon, Donaldson, Burns & Tarrier (1998) United Kingdom	AD spouse with low intimacy	36	77.3 (SD 8.1)	36	56	43	63.2 (SD 13.6)	CFI	5.11 (4.15)	0.77 (1.21)	1.51 (1.04)	-
	AD spouse with high intimacy	63		63				CFI	2.87 (1.07)	0.36 (0.9)	1.16 (1.07)	-
Tarrier et al. (2002) United Kingdom	Dementia relatives	100	77.3 (SD 8.1)	100	57	43	63.1 (SD 13.6)	CFI	3.7 (3.5)	-	-	-
Hanson & Clarke (2013) England	MCI & dementia spouse	46	76.98 (SD 5.35)	46	33	13	74.04 (SD 7.09)	FMSS	-	-	-	44% participants
Li & Lewis (2013) Taiwan	Dementia relatives	65	78.8 (SD 7.5)	65	47	18	59.7 (SD 13.3)	LEE	-	-	-	13.63 (7.62)
Lim et al. (2011) Singapore	Dementia family	107	78 (SD 8.9)	109	77	32	49 (SD 10.8)	Brief COPE	3.2 (1.1)	-	2.8 (1.1)	-
Ott, Sanders & Kelber (2007) U.S.A.	AD family	201	-	201	162	39	64.07 (SD 13.88)	Brief COPE	2.17 (0.77)	-	2.28 (0.89)	-
Hinrichsen & Niederehe (1994) U.S.A.	Dementia Family	152	77.9 (SD 7.3)	152	107	45	59.6 (SD 14)	DMSS	2.34 (0.80) per item ≈ 25.74 on the scale	-	-	-
Lim et al. (2011) Singapore	Dementia family	107	78 (SD 8.9)	109	77	32	49 (SD 10.8)	DMSS	23.1 (6.9)	-	-	-
McCurry et al. (2006) USA	Probable /possible AD relatives	46	63–93	46	30	16	21–87	DMSS	23.5 (6.3)	-	-	-

Note. CFI high expressed emotion indicated by Criticism scores 6+ or hostility scores 1+ or Emotional Over-involvement 3+. FMSS high expressed emotion indicated by Criticism scores 1+ or hostility scores 1+ or Emotional Over-involvement 1+. LEE high expressed emotion indicated when total score is 20.7 or higher. Brief COPE subscale scores range from 2 (do not use this coping strategy) to 8 (usually use this coping strategy). DMSS criticism subscale scores range from 11 (never use the behaviour) to 55 (use the behaviour most of the time).

In sum, in eight studies with 818 caregiver participants, results demonstrated the presence of varying degrees of elevated expressed emotion in the form of criticism, venting negative emotions, hostility, emotional overinvolvement, and self-blame in unpaid caregivers of people with dementia. Specifically, in the six studies that reported mean EE scores, 65% of the results indicated minimal levels of EE and 32% of the results indicated moderate levels of EE in these caregivers. One study representing 2% of participants reported results in terms of percentage of participants and found 44% of the 46 participant caregivers demonstrated high levels of EE. The chart in Figure 3 depicts a comparison of coping and expressed emotion results.

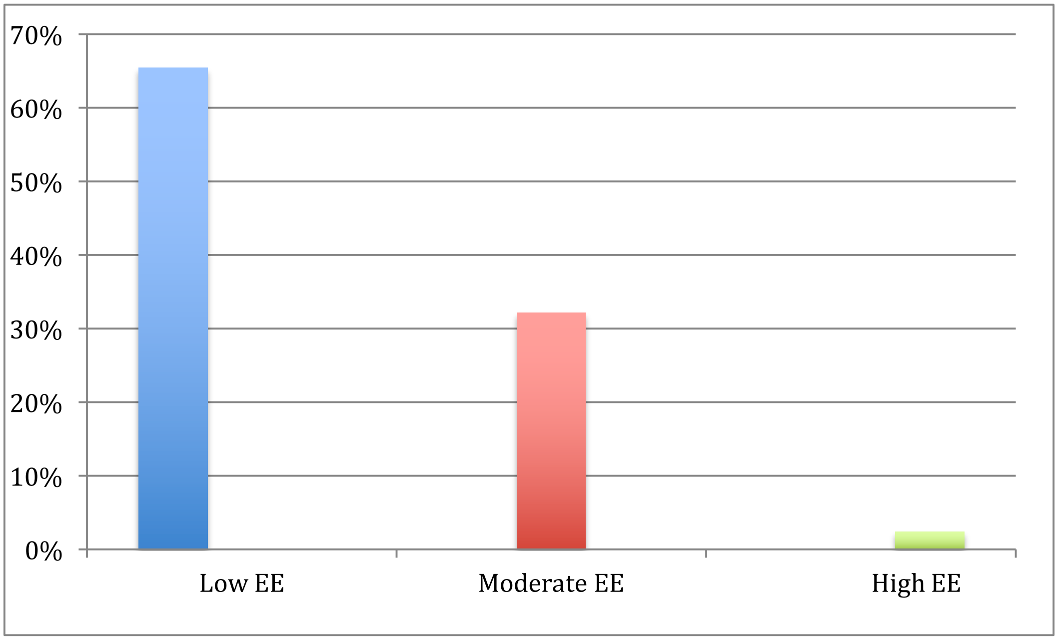


Figure 3. Comparison of coping and expressed emotion results.

Coping strategies associated with lower subjective burden. Of the 53 full-text papers assessed for review, seven of the studies included coping strategy measures. Three of these studies found significant associations between lower subjective burden and caregivers coping by using encouragement with the care recipient (Hinrichsen & Niederehe, 1994; Liew et al., 2010; Lim et al., 2011). The use of active coping by making efforts to modify the environment, stimulate and distract the care recipient from uncomfortable feelings was found to be significantly associated with lower burden in three studies (Liew et al., 2010; McConaghy & Caltabiano, 2005; Zucchella et al., 2012), but in one study active coping was significantly associated with higher burden (Hinrichsen & Niederehe, 1994). Of note, in one of these studies (Zucchella et al., 2012) caregivers demonstrated lower subjective burden when they coped by using active problem solving strategies early in the disease whereas this style had less impact on subjective burden later in the disease. One study found correlations between caregivers' endorsement of personal growth with coping by reframing and religion (Ott, Sanders, & Kelber, 2007). Finally, one study did not find any significant correlations between coping style and lower subjective burden (Cooper, Owens et al., 2008).

Psychological Distress

In twelve studies, psychological distress in the form of depressive symptoms in unpaid caregivers of people with dementia was rated from the Beck Depression Inventory (BDI), Brief Symptom Inventory (BSI), Center for Epidemiological Studies Depression Scale (CES-D), Hospital Anxiety and Depression Scale (HADS), and Geriatric Depression Scale (GDS). The instruments were administered by a variety of organizations in Canada, Cyprus, Italy, Spain, United Kingdom, and the U.S.A. using the versions translated into their respective languages. Studies were published between 1999 and 2014. Samples were taken from relatives and family members of people with probable Alzheimer's disease and dementia. Patients were residing at home or in an institution. The results are shown in Table 3.

The BDI was used to measure caregivers' psychological distress in three studies, each from a different organization and published between 1999 and 2014 (Garcia-Alberca et al., 2014; Miller, Rosenheck, & Schneider, 2010; Zanetti et al., 1999). Sample sizes ranged from 80 to 421, with a combined total of 601 participants. Mean ages of caregivers ranged from 54.6 to 63 years; 455 of the participants were female and 146 were male. Results from two of the studies showed BDI mean scores ranging from 8.4 to 8.72, indicating minimal depression. In contrast, one study (Garcia-Alberca et al., 2014) resulted in a BDI mean score of 28.11, indicating moderate depression.

The BSI depression subscale was used to measure caregivers' psychological distress in two studies published in Italy by discrete organizations in 2004 and 2005. (Aguglia et al., 2004; Rinaldi et al., 2005). Sample sizes were 231 and 419 respectively, with a total of 458 females and 192 males. Caregiver mean age ranged from 58.2 to 64.7 years. Results from the two studies showed the sum of the means of the six items on the Depression subscale ranged from 5 to 5.8. For the purposes of comparing these scores to the normative samples, the sum of means was divided by the six items, resulting in Depression subscale mean scores ranging from 0.83 to 0.96. As such, none of the samples demonstrated clinical levels of distress on this subscale.

Table 3

Studies that have measured caregivers' psychological distress with the Beck Depression Inventory (BDI), Brief Symptom Inventory (BSI), Center for Epidemiological Studies Depression Scale (CES-D), Hospital Anxiety and Depression Scale (HADS), and the 15-item Geriatric Depression Scale (GDS).

Study description (Author/Year/Country)	Sample	Patient		Carer				Measure	Mean (SD)
		N	Age	N	Fem	Male	Age		
Garcia-Alberca et al. (2014) Spain	AD relatives	80	77.34 (SD 5.74)	80	62	18	62.15 (SD 10.37)	BDI*	28.11 (8.76)
Miller, Rosenheck & Schneider (2010) U.S.A.	AD relative	421	77.9 (SD 7.5)	410	320	90	63 (SD 15.5)	BDI	8.4 (7.33)
Zanetti et al. (1999) Italy	Dementia relative	111	74.4 (SD 8.4)	111	73	38	54.6 (SD 13.1)	BDI	8.72 (8.0)
Aguglia et al. (2004) Italy	AD female relative	-	-	231	156	0	61.1 (SD 13.1)	BSI Depression	Sum of means =5.3 (0.9) Mean = 0.88
	AD male relative				0	75	64.7 (SD 13.6)	BSI Depression	Sum of means=5 (1.3) Mean = 0.83
Rinaldi et al. (2005) Italy	Dementia relative	419	75.8 (SD 7.7)	419	302	117	58.2 (SD 14.1)	BSI Depression	Sum of means=5.8 (5.2) Mean = 0.96
Cohen, Colantonio & Vernich (2002) Canada	Dementia relative	289	84.4	289	198	91	64 (range 29-96)	CES-D	6.43 (8.49)

(continued)

Study description (Author/Year/Country)	Sample	Patient		Carer				Measure	Mean (SD)
		N	Age	N	Fem	Male	Age		
Elliott, Burgio & DeCoster (2010) U.S.A.	AD relatives Hispanic	169	-	169	-	-	-	CES-D	10.6 (7.2)
	AD relatives White	160	-	160	-	-	-	CES-D	9.9 (5.9)
	AD relatives African American	166	-	166	-	-	-	CES-D	9.2 (6.1)
Papastavrou et al. (2007) Cyprus	Probable AD family living at home	130	74.5	130	-	-	56.8 (SD 13.38)	CES-D*	18.68 (7.27)
Papastavrou et al. (2012) Cyprus	Dementia family members	168	-	168	-	-	56.8 (SD 13.3)	CES-D*	16.7 (10.9)
Tremont et al. (2013) U.S.A.	Dementia family	250	78.06 (SD 10.06)	250	195	55	62.72 (SD 12.99)	CES-D*	16.35 (9.99)
Cooper, Owens, Katona & Livingston (2008) United Kingdom	AD relative	83	82.2	83	52	31	64.2 (SD 15.4)	HADS Depression	3.5 (2.9)
Gaugler, Mittelman, Hepburn & Newcomer (2010) U.S.A.	Dementia relative	1610	71.47 (SD 7.62)	1610	-	-	63.56 (SD 14.42)	15-item GDS*	35.8% scored 6 or higher

Note. BDI mild depression indicated by scores 10-18, moderate depression indicated by scores 19-29, severe depression is indicated by scores 30-63. BSI Depression subscale psychological distress indicated for total participants by scores ≥ 1.46, for females by scores ≥ 1.62, for males by scores ≥ 1.11. CES-D none to minimal depression indicated by scores 0-15.16, mild to moderate depression indicated by scores 15.17 to 20, moderate to severe depression indicated by scores 21+. HADS Depression subscale normal mood indicated by scores 0-7, borderline abnormal mood indicated by scores 8-10, abnormal mood indicated by scores 11-21. 15-item GDS normal mood indicated by scores 0-5, depression suggested by scores 6-10, depression almost always indicated by scores 11-15.

* Results suggest evidence of depression.

The CES-D was used to measure caregivers' psychological distress in five studies, two of which originated from the same institution using discrete samples (Papastavrou et al., 2007; Papastavrou et al., 2012), and the other three from different organizations (Cohen, Colantonio, & Vernich, 2002; Elliott, Burgio, & DeCoster, 2010; Tremont et al., 2013). The studies were published between 2002 and 2013. Sample sizes ranged from 130 to 289, with a combined total of 1,332 participants. Ages of caregivers ranged from 29 to 96 years, with means reported on 3 of the studies ranging from 56.8 to 62.72 years; of note, one study did not report ages of caregivers (Elliott, Burgio & DeCoster, 2010). Only 2 studies reported gender counts: Cohen, Colantonio, & Vernich (2002) reported 198 female and 91 male caregivers; Tremont et al. (2013) reported 195 female and 55 male caregivers. Results from two of the studies showed CES-D mean scores ranging from 6.43 to 10.6, indicating none to minimal depression (Cohen, Colantonio & Vernich, 2002; Elliott, Burgio & DeCoster, 2010). In contrast, three studies (Papastavrou et al., 2007; Papastavrou et al., 2012, Tremont et al., 2013) resulted in CES-D mean scores ranging from 16.35 to 18.68, indicating moderate depression.

The HADS depression subscale was used to measure caregivers' psychological distress in one study published in the United Kingdom in 2008 (Cooper, Katona et al., 2008). The sample was a group of 83 caregivers, 52 female and 31 male. The mean age of caregivers was 64.2 years. Results showed a CES-D depression subscale mean score of 3.5, indicating normal mood.

The 15-item GDS was used to measure caregivers' psychological distress in one study published in the United States in 2010 (Gaugler et al., 2010). The sample was a group of 1,610 caregivers of unspecified gender. The mean age of caregivers was 63.56 years. Results showed that 35.8% of the sample caregivers scored above the cutoff point of 6, suggesting depression.

In sum, in twelve studies with 4,276 caregiver participants, 7 studies (2,038 participants – 47.7%) showed a mean score below the clinical cutoff for psychological distress in terms of depressive symptoms, and 5 studies (2,238 participants – 52.3%) showed a mean score above the clinical cutoff for psychological distress in terms of depressive symptoms. The chart in Figure 4 depicts a comparison of psychological distress results.

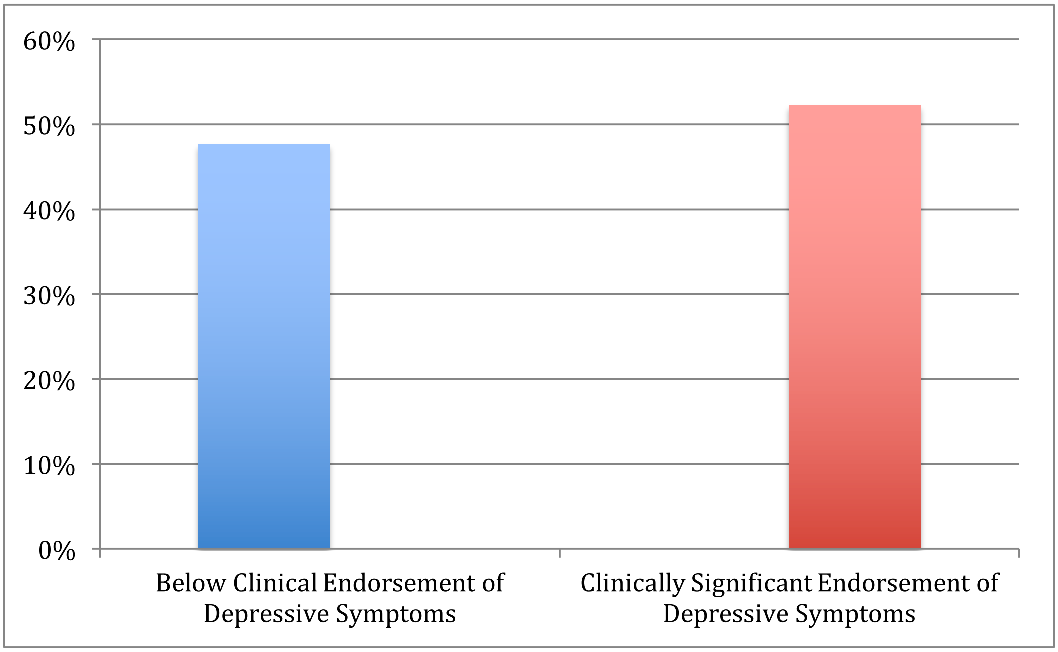


Figure 4. Comparison of depressive symptoms results.

Chapter 4: Discussion

This review identified 31 papers containing 44 data sets on measures of subjective caregiver burden, expressed emotion, and/or psychological distress for unpaid caregivers of people with dementia. The results from this synthesis have considerable clinical implications for understanding the needs of unpaid family caregivers for people with dementia. The findings are consistent with previous studies in which these caregivers experience higher distress from burden and depression than their peers (Alzheimer's Association, 2015; National Alliance for Caregiving & AARP, 2009). The findings also reveal that some caregivers express criticism of the care recipient and emotional overinvolvement as ways of coping with their distress, which have unhealthy effects on themselves and their care recipients (Cooper, Katona, Orrell, & Livingston, 2008; Huang et al., 2013). Practitioners can draw from the more effective coping strategies employed by the majority of caregivers when intervening to support their dementia patient-caregiver pairs.

It is noteworthy that less than one quarter of the studies included descriptive statistics about the ethnicity of the caregivers, one-fifth described the ethnic language of the caregivers, and fewer described the socioeconomic status of the caregivers. Future research may benefit from incorporating cultural descriptors of caregivers so that clinicians will be better able to understand potentially different trends and coping strengths or needs of varied cultural groups.

Caregiver Burden

An abundance of literature was found pertaining to subjective caregiver burden and only data from the two most commonly used instruments (ZBI and CBI) were included in this review. While a more inclusive review may have resulted in a different clinical picture, the large sample of 5,249 participants from 20 countries can be considered a representative sample of the caregiver population. A synthesis of the data sets revealed that subjective caregiver burden measured with the ZBI and CBI has a distribution skewed to the left, with most caregivers demonstrating moderate-high subjective burden, and more high-severe subjective burden endorsements than low subjective burden endorsements. This trend describes a predominating experience of strain and hardship for unpaid family caregivers of people with dementia.

The findings of the present study are consistent with recent findings from the Alzheimer's Association (2014) whose survey of 3,102 caregivers for people with dementia, weighted to match the most recent U.S. census demographics for gender, age, education, ethnicity, and region, reported 59% of caregivers rated their the emotional stress of caregiving as high or very high. Given the ramifications of high subjective burden on the caregiver's physical and psychological wellbeing as well as on the patient's behavioural symptoms, it will be important for medical and mental health professionals to monitor and address caregiver burden throughout the course of the dementia illness.

Coping and Expressed Emotion

In terms of expressed emotion, this review aimed to understand caregivers' coping behaviours in their relationships with the care recipients. This area of inquiry revealed the smallest number of studies pertaining to caregivers for people with dementia, and as a result this review imposed the most lenient restrictions for data inclusion. The data collected is likely representative of the available evidence relating to expressed emotion, specifically, criticism as a coping response. Future research may produce a better clinical picture of how caregivers of people with dementia tend to cope.

Caregiver levels of expressed emotion measured with a variety of instruments showed a distribution skewed to the right, with most outcomes indicating low EE, approximately a third of outcomes indicating moderate EE, and minimal outcomes with overall high EE. This trend reveals that few caregivers of people with dementia cope with the strain and distressing aspects of their role by criticizing the care recipient or feeling hostile or overly emotionally involved in the care recipient's difficulties. However, future research may benefit from specific investigation of how the stage of dementia may impact family members' coping and use of EE.

Looking at the studies that measured EE constructs with coping instruments, it can be seen that caregivers experienced lower subjective burden when they cope by using encouragement with their loved ones who have dementia. In addition, most of the caregivers who took an active approach in modifying the environment and seeking ways to stimulate and distract their care recipients from discomfort endorsed lower subjective burden. Clinicians can help relieve caregivers by providing support for them to develop coping strategies that may reduce their experiences of burden in the caregiving role. The caregivers in many of the included studies were involved in support programs as a part of their participation in research interventions. It is recommended that greater attention be given to exploring how to implement the effective aspects of these interventions to the broader and more diverse community.

Psychological Distress

With regards to psychological distress, this review sought to include symptoms of anxiety and depression experienced by caregivers; however, the search unearthed a paucity of data sets for anxiety measures and the results were limited to measures of depression. Distress can manifest itself with different symptoms and the clinical picture may have been different had this review included caregivers reporting anxiety. Nevertheless, the large sample of 4,276 participants from 6 countries can be considered a representative sample to estimate patterns of depressive distress in caregivers.

Caregiver distress in terms of depressive symptoms was clinically elevated in more than half of the sample. The prevalence of depression encapsulated by the present study is higher than Schoenmakers et al.'s (2010) metaanalysis of 13 studies that found 1/3 of caregivers for people with dementia experience depression. Differences in inclusion criteria between Schoenmakers et al.'s metaanalysis and the present study may partly explain the discrepancy in findings (e.g., Schoenmakers included studies dated 1990 – 2009). However, studies in their metaanalysis showed a range of 30% to 80% of depression rates in caregivers, depending on the population and recruiting method used by the independent studies, which is consistent with the range and mean of depression prevalence found herein. The pressing need for mental health care in caregivers of people with dementia is highlighted when compared to the general population; specifically, U.S. prevalence of depression in the general population is 6.7% (Kessler, Chiu, Demler, & Walters, 2005) and the world prevalence of depression is 3.2% (Moussavi et al., 2007).

Both Schoenmakers et al. and the present study's results emphasize the widespread need for psychological intervention in caregivers for people with dementia. In the majority of cases synthesized herein, the important role caregivers play in maintaining the health and dignity of their vulnerable family member was impacted by the severity of the caregiver's own need for psychological care. Future interventions to reduce depression should focus on educating practitioners who treat dementia patients, such as neurologists and neuropsychologists, about the importance of recognizing and treating caregivers as part of integrated care for dementia patients. Attention to caregivers' psychological distress should not be treated as adjunctive but rather as critical to the effective care of the dementia patient.

Strengths and Limitations of the Present Review

This dissertation will potentially benefit medical and psychology practitioners and the dementia patients and families for whom they provide care by providing a description of the nature and prevalence of distress related to the caregiving role. The descriptions derived from this data synthesis will alert practitioners to the importance of identifying and addressing caregivers' needs for intervention.

Results describing the caregivers varied across studies. A possible explanation for the dissimilar findings include heterogeneity of culture, language and age of the participants, differences in relationships between the participants and the care recipients. The diversity of the included data sets underscores the usefulness of a systematic review and synthesis of studies for the purpose of generalizing the findings to a broader population of caregivers. As such, the results of this review give an expanded clinical picture of unpaid voluntary caregivers for people with dementia.

Conversely, despite the appearance of diverse representation by the synthesized samples, there may be subcultures from each country that were not included in the studies. This possibility must be considered and caution used when translating the results to minority subcultures. Furthermore, despite the strength of including diverse samples in the synthesis, the variability in sample sizes between studies may have influenced the findings to be more representative of some groups than others. For example, in the results for depressive symptoms, the largest sample came from the United States. The discrepancy in sample sizes was less apparent for the subjective burden and EE results.

Another possible explanation for the varied results between studies is the difference in operationalization of key concepts in the instruments used to measure the constructs of subjective burden, EE, and depression. For example, the CFI interprets critical comments and emotional overinvolvement from a two-hour long interview, whereas the FMSS interprets the same constructs from a five-minute interview, and the DMSS infers the construct from a forced choice self-report questionnaire. While the key constructs of this dissertation (i.e., caregiver burden, expressed emotion, depression) were each measured by multiple instruments, efforts were made to ensure the key constructs were defined as similarly as possible between the instruments.

All studies included in the review were assessed for their use of well-established instruments and reporting of quantitative data in describing the participants. The restrictions subsequently applied to the data strengthened the comparability of the included data sets. The broadness of the review process was limited by inclusion only of papers that published the means, standard deviations and number of participants. A more extensive search could include seeking the original data sets from the researchers who did not publish them. Further, the review process only searched articles published in the English language; therefore, data representing numerous cultures was excluded as a matter of course. Data published in English is more likely to come from studies with significant results. A systematic review would be better able to describe the population when data from studies with null results are also included.

As noted in the results, while this synthesis included studies from multiple nations, the ethnicity and socioeconomic aspects of the caregivers was reported in only a minority of the included studies. Nevertheless, the participants of the synthesized studies were from multiple cultures or subcultures and may have felt different pressures to answer the questions on the instruments in different ways reflective of the values in their cultures. For example, participants from collectivistic cultural backgrounds may have been more likely to feel social pressure to minimize the impact of burden compared to participants from individualistic cultural backgrounds. Using the mean score derived from a high number of participants helped adjust the impact of response bias on the results. Finally, The participants of synthesized studies were all volunteers. It is possible that samples of volunteers would differ from nonvolunteers in how they answered questions on the instruments included in this dissertation.

Conclusion

This review presented characteristics and experiences of caregivers who participated in research studies between 1994-2014. Areas of concern for practitioners with patients who are unpaid caregivers of people with dementia were summarized. Specifically, the majority of caregivers require clinical support for the high subjective burden related to their relationship with the care recipient, and approximately half of caregivers were experiencing clinically significant levels of depressive symptoms that may threaten their own physical health and the wellbeing of their loved one with dementia. In the studies included in this review, the majority of caregivers demonstrated minimal levels of expressed emotion. Comparatively fewer studies have been published investigating the role of expressed emotion in the coping styles of caregivers of people with dementia. However, supporting caregivers to increase encouragement and engagement with their loved ones may be a useful intervention for reducing their experience of distress from burden. Future research into coping styles of caregivers of people with dementia may be useful for understanding how to provide treatment and support that will alleviate subjective burden and depression for this ever-growing population of caregivers.

Caregivers for dementia patients are an underserved population who perform a great service not only to their loved one's quality of life but also to reducing financial strain on our medical/healthcare systems by being unpaid volunteers for a highly dependent group of people in our societies. The results of the present systematic review of the literature underscore a deficit in our social and/or healthcare policies with regards to the unpaid family caregivers for patients with dementia. The findings show that these caregivers are grossly undersupported and in significant distress. Future research may explore how to extend resources to caregivers for patients with dementia beyond basic provision of the patient's diagnosis and medical care. Moving in this direction is important not only to optimize care of the dementia patient, but also to contribute to preventing negative health outcomes among caregivers.

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APPENDIX A
Comprehensive Literature Table

Comprehensive Literature Table

	Article	Annotation	Burden Instrument	EE Instrument	Distress Instrument	Syndrome studied
1.	Aguglia, E., Onor, M. L., Trevisiol, M., Negro, C., Saina, M., & Maso, E. (2004). Stress in the caregivers of Alzheimer's patients: An experimental investigation in Italy. *American Journal of Alzheimer's Disease and Other Dementias, 19*, 248–252.	Outlines "economic & social costs" of caregiving. Outcome: financial burden of caregiving (i.e., reducing paid work hours to be at home with patient) impacts scores on BSI & CBI. - males report significantly less physical strain than females - low MMSE associated with high CBI & BSI - low ADL/IADL associated with high CBI & BSI	CBI	(none)	BSI (Brief Symptom Inventory)	Dementia
2.	Alzheimer's Association. (2014). 2014 Alzheimer's disease facts and figures, *Alzheimer's and Dementia, 10*(2), e47–e92.	- 2014 telephone survey to 3,102 caregivers for people with dementia, weighted to match the most recent U.S. census Demo-graphics for gender, age, education, ethnicity, and region, and telephone service reported 59% of caregivers rated their the emotional stress of caregiving as high or very high	(none)	(none)	(none)	Demo-graphics
3.	Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. *Alzheimer's and Dementia, 11*(3), 332–384.	AD 6th leading cause of death in USA, only cause of death in the top 10 in USA that cannot be prevented, cured or slowed, 1/3 of seniors die with AD or other dementia 15.7 million ppl in USA are unpaid family or friend caregivers for AD, dementia, mental confusion 75% of ppl with dementia who are not in residential facilities live at home with caregiver, the other 25% live alone. Chronic stress of caregiving more likely to have cardiovascular disease and impaired kidney fn, reduced immune function, slow wound healing	(none)	(none)	(none)	Demo-graphics

4.	Alzheimer's Association (2012). Alzheimer's disease facts and figures, *Alzheimer's and Dementia, 8*(2), 1–72.	AD is 6th leading cause of death in USA. 15 million Americans are unpaid caregivers for dementia. Breakdown of Demographics incl tasks, estimate of hours spent per annum, fiscal value to nation because unpaid. Outlines caregiver roles. Costs of longterm care services. 800,000 people with AD live alone in USA – increased risk for neglect, injury, psychological distress	(none)	(none)	(none)	Demographics
5.	Akpinar, B., Küçükgüçlü, Ö., & Yener, G. (2011). Effects of gender on burden among caregivers of Alzheimer's patients. *Nursing Scholarship, 43*(3), 248–254.	Gender comparison in burden. Outcome: males experienced higher burden in terms of time dependence, developmental, social & physical burden. Males & females no difference in terms of emotional burden.	CBI	(none)	(none)	Dementia
6.	American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.	Diagnostic criteria.	(none)	(none)	(none)	(none)
7.	Anthony-Bergstone, C. R., Zarit, S. H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging, 3*(3), 245–248.	Outcome: hostility and anxiety are elevated for caregivers significantly ore than normative population. Depression is significantly elevated for older female caregivers compared to normative population.	Zarit	(none)	BSI	Dementia
8.	Arai, Y., Zarit, S. H., Sugiura, M., & Washio, M. (2002). Patterns of outcome of caregiving for the impaired elderly: A	- the majority of caregivers in this study showed decreases in burden over the course of a year, suggesting adaptation to role. - those who had highest ZBI at beginning of study	Zarit	(none)	(none)	Disabled elderly

	longitudinal study in rural Japan. *Aging and Mental Health, 6*(1), 39–46.	were most likely to give up caregiving by finding an alternate caregiver or by institutionalizing the patient -those who were caring for an individual with dementia were significantly less likely to successfully adapt to their role of caregiver over time (ZBI scores did not significantly reduce after 1 year compared to nondementia)				
9.	Arai, A., Matsumoto, T., Ikeda, M., & Arai, Y. (2007). Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia? *International Journal of Geriatric Psychiatry, 22*, 1255–1261.	Comparison between caregivers of patients with onset younger than 64 years and caregivers of patients 65+ years old. Outcome: Despite similar patient functioning, early onset caregivers rated their difficulties coping with behavioural disturbances as more severe than late onset caregivers but did not endorse higher burden. Maybe perceived difficulty is a precursor to burden.	Zarit	(none)	GHQ-28	Dementia
10.	Beck, A. T., Steer, R. A., & Brown, G. K. (1996). *Beck Depression Inventory-II.* San Antonio, TX: Pearson.	BDI-II 0-13 minimal 14-19 mild depression 20-28 moderate depression 29-63 severe depression	(none)	(none)	(none)	(none)
11.	Beck, A. T., Steer, R. A., & Garbin, M. G. (1988). Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review, 8*, 77–100.	BDI <10 none-minimal 10-18 mild to moderate 19-29 moderate to severe 30-63 severe	(none)	(none)	(none)	(none)
12.	Bédard, M., Molloyo, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The	12-item version of Zarit Burden Interview is highly comparable to the standard 22-item version.	Zarit	(none)	(none)	Dementia

	Zarit Burden Interview: A new short version and screening version. *Gerontologist, 41*(5), 652–657.					
13.	Benoit, M., Robert, P. H., Staccini, P., Brocker, P., Guerin, O., Lechowshi, L., & Vellas, B. (2005). One-year longitudinal evaluation of neuropsychiatric symptoms in Alzheimer's disease. The REAL.FR study. *Journal of Nutrition, Health and Aging, 9*(2), 95–99.	Outcome: AD patients who have lower MMSE, higher agitation and higher disinhibition ratings, and higher Zarit caregiver burden score are significantly more likely to be institutionalized within 12 months compared to other AD patients	Zarit	(none)	(none)	Dementia
14.	Berger, G., Bernhardt, T., Weimer, E. Peters, J., Kartzch, T., & Frolich, L. (2005). Longitudinal study on the relationship between symptomatology of dementia and levels of subjective burden and depression among family caregivers in memory clinic patients. *Journal of Geriatric Psychiatry and Neurology, 18*(3), 119–128.	Also measured patients' dementia severity over time. ZBI/BDI/GDS administered at baseline *(n* = 45), 3 months (*n* = 45), 6 months (*n* = 42), 12 months (*n* = 34), and 24 months (*n* = 18). Outcome: correlation between patient's severity and caregiver burden and caregiver depression is significant at 12 months and more strongly significant at 24 months. Not significant level at other times.	Zarit	(none)	GDS BDI	Dementia
15.	Bledin, K. D., MacCarthy, B., Kuipers, L., & Woods, R. T. (1990). Daughters of people with dementia. Expressed	Outcome: High EE in daughters caring for parents with dementia significantly correlated with higher levels of strain and distress.	(none)	CFI	(none)	Dementia

	emotion, strain, and coping. *British Journal of Psychiatry, 157,* 221–227.					
16.	Boland, A., Cherry, M. G., & Dickson, R. (Eds.). (2013). *Doing a systematic review: A student's guide.* Los Angeles, CA: Sage.	-"lit review designed to locate, appraise and synthesize the best available evidence relating to a specific research question to provide informative and evidence –based answers. This info can then be combined w professional judgment to make decisions about how to deliver interventions or to make changes to policy." 9 steps in systematic review process: 1) identify a review question 2) literature search of databases to i.d. papers related to my review question 3) screen titles and abstracts and discard irrelevant, keep relevant 4) obtain full-text papers 5) apply inclusion criteria and ruthlessly exclude ones that don't fit my criteria 6) assess full-text papers for methodological quality and appropriate quality assessment tool 7) identify the data I require from each paper and summarize the data in tables 8) Synthesize data using narrative synthesis or meta-analysis. 9) Write up background, methods, results, discussion of findings and draw conclusion.	(none)	(none)	(none)	Systema-tic review method-logy
17.	Brashares, H. J., & Catanzaro, S. J.	Outcome: positive correlation between active	Zarit	Generalize d	Research and	Dementia

	(1994). Mood regulation expectancies, coping responses, depression, and sense of burden in female caregivers of Alzheimer's patients. *Journal of Nervous and Mental Disease, 182*, 437–442.	coping (problem solving) and depressive symptoms in caregivers. Usually active coping is related to higher functioning but seems when stressors are beyond control (as in dementia) caregivers accustomed to active coping are unsuccessful and become discouraged. Support caregivers by increasing negative mood regulation skills, i.e., target feeling upset with active coping rather than targeting the dementia symptoms.		Expectancy for Negative Mood Regulation Scale (NMR)	Diagnostic Criteria	
18.	Brink, T. L., Yesavage, J. A., Lum, O., Heersema, P., Adey, M. B., & Rose, T. L. (1982). Screening tests for geriatric depression. *Clinical Gerontologist, 1*, 37–44.	GDS-15 (Short Form) >5 suggests depression >10 almost always depression	(none)	(none)	(none)	(none)
19.	Brodaty, H. & Arasaratnam, C. (2012). Meta-analysis of nonpharmacological interventions for neuropsychiatric symptoms of dementia. *American Journal of Psychiatry, 169*(9), 946–953.	Use as example for tables & flowchart? Metaanalysis performed using "review manager" = standardized mean differences btwn pre- and post tx assessments used to determine effect sizes btwn 1600 articles. Used 23 studies in final review. Outcome: signif improvement or neutral outcomes based on reduced behavioural and psychological sx frequency or severity for persons with dementia. Signif improvement or neutral outcomes based on subsidiary scales on Neuropsych inventory and the Revised memory and Beh Problem Checklist. Recommend: 9 to 12 sessions tailored to needs of dyad delivered individually in the home over 3-6 mos with periodic follow up	(none)	(none)	(none)	Recommendations
20.	Brown, G. W., Birley, J. L. T., & Wing, J. K. (1972).	Patients discharged from hospital in Camberwell, UK with probable schizophrenia dx then	(none)	Camberwell Family Interview	(none)	Schizophrenia

	Influence of family life on the course of schizophrenic disorders: A replication. *British Journal of Psychiatry, 121*, 241–258.	readmitted within 5 years were interviewed multiple times and family were interviewed at home at time of admission then again 9 months after discharge. Family members' interviews were rated for frequency of critical comments, hospitality, dissatisfaction, warmth, and emotional over-involvement and an overall index of relative's expressed emotion was calculated. Outcome: 9 months after discharge High EE 58% relapse Low EE 16% relapse 0 critical comments 19% relapse 1-6 critical comments 26% relapse 7+ critical comments 57% relapse Hostility not evident 32% relapse Hostility evident 50% relapse 0-3 emotional overinvolv 36% relapse 4-5 emotional overinvolv 62% relapse Warmth not included in overall index. Hi warmth +ve related to emo overinv Lo warmth +ve related to critical com In few cases when warmth was not related to either crit or emo overinv, only 1/11 patients relapsed (9%)				
21.	Brown, G. W., Carstairs, G. M., & Topping, G. (1958). Post-hospital adjustment of chronic mental patients. *Lancet, 2*(7048), 685–688.	All disorder types had approximately 32% readmission to hospital for similar symptoms in less than 1 year. For patients with schizophrenia, a relationship was found between post-discharge living arrangements and readmission in less than 1 year. I.e., patients living in large hostel or with parents, wives had more readmissions than other types of lodging or living with siblings	(none)	(none)	(none)	Schizophrenia Depression Epilepsy Psychoses Psychoneuroses Other

22.	Brown, G. W., Monck, E. M., Carstairs, G. M., & Wing, J. K. (1962). Influence of family life on the course of schizophrenic illness. *British Journal of Preventive and Social Medicine, 16*, 55–68.	p. 57 describes rating scale for expressed emotion, dominating behaviour, and expressed hostility. High EE = uncontrolled emotional frequently shown in the interview. Outcome: High EE 8/9 patients rehospitalized (89%) Moderate EE 18/24 patients rehospitalized (75%) Minimal EE 23/55 patients rehospitalized (42%) Low EE 2/9 patients rehospitalized (22%) Similar outcomes on hostility and dominance scales. Patients discharged to highly emotional family situations where they lived had significantly higher rate of worsening symptoms and were rehospitalized in less than one year.	(none)	Camberwell Family Interview	(none)	Schizo-phrenia
23.	Butzlaff, R. L., & Hooley, J.M. (1998). Expressed emotion and psychiatric relapse: A meta-analysis. *Archives of General Psychiatry, 55*(6), 547–552.	EE of family members predicts schizophrenia patient relapse with strong effect size when critical comments are 6 or more. EE of family members predicts depression patient relapse with strong effect size when critical comments are 3 or more, suggesting EE is a stronger predictor of outcome for depression than it is for schizophrenia. EE of family members predicts eating disorder patient relapse with strong effect size when critical comments are slightly lower than schizophrenia, suggesting similar or stronger prediction value.	(none)	CFI	(none)	Schizo-phrenia Depres-sion Eating Disorder
24.	Cannuscio, C. C., Jones, C., Kawachi, I., Colditz, G. A., Berkman, L., & Rimm, E. (2002). Reverberations of family illness: A longitudinal assessment of informal	Women who had been spousal or parent caregivers reported 2x more likelihood than noncaregivers to experience depressive or anxious symptoms in the 4 years following the end of their caregiving role. Women who reported caregiving as rewarding were 50% less likely to experience	(none)	(none)	(none)	Demo-graphics

	caregiving and mental health status in the nurses' health study. *American Journal of Public Health, 92*(8), 1305–1311.	anxiety/depressive sx than women who reported it not at all rewarding.				
25.	Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4*(1), 92–100.	Scales with most value in previous research on full version were kept and reviewed for criteria with highest loading on the relevant factors to create faster to administer version. Venting: I've been saying things to let my unpleasant feelings escape. I've been expressing my negative feelings. Self-Blame: I've been criticizing myself. I've been blaming myself for things that happened.	(none)	Brief COPE	(none)	Commun-ity recovering from hurricane
26.	Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56*(2), 267–283.	Created Coping Orientations to Problems Experienced inventory based on Lazarus' concepts of coping. Used 13 scales and compared with personality traits to validate.	(none)	COPE	(none)	Undergrad-uate students
27.	Caserta, M. S., Lund, D. A., & Wright, S. D. (1996). Exploring the Caregiver Burden Inventory (CBI): Further evidence for a multidimensional view of burden. *International Journal of Aging and Human Development, 43*(1), 21–34.	"Most of the variability in physical burden was explained by depression." Depression and caregiving satisfaction explained by feeling "deprived" of doing what they wanted or expected at this point in their lives. Outcome: - time dependence burden correlated with patient functioning and # of caregiving tasks. - developmental burden correlated with depression, fewer positive aspects of caregiving, patient functioning, and caregiver sick days - physical burden correlated with sick days, patient	CBI	(none)	CES-D	Dementia

		functioning, fewer positive aspects of caregiving, and strongly with depression - social burden correlated with depression, caregiver sick days - emotional burden correlated with depression and fewer positive aspects of caregiving				
28.	Centers for Disease Control and Prevention [CDC]. (2009). Caregivers of persons with Alzheimer's disease or dementia in Illinois, Louisiana, Ohio, and the District of Columbia. *Behavioural Risk Factor Surveillance System Survey Data*. Atlanta, GA: U.S. Department of Health and Human Services.	Illinois, Louisiana, Ohio, Washington DC telephone surveys. For AD/dementia, care recipient is: Parent/parent-in-law 62.9% Spouse 7.8% Other relative 21.7% Non relative 7.6% Significantly higher (p<0.05) difficulty than non-dementia caregivers "creates or aggravates health problems" and "creates stress"	(none)	(none)	(none)	Demo-graphics
29.	Centers for Disease Control and Prevention [CDC]. (2010). Caregivers of persons with Alzheimer's disease or dementia in Connecticut, New Hampshire, New Jersey, New York, and Tennessee. *Behavioural Risk Factor Surveillance System Survey Data*. Atlanta, GA: U.S. Department of Health and Human Services.	Connecticut, New Hampshire, New Jersey, NY, Tennessee telephone surveys. For AD/dementia, care recipient is: Parent/parent-in-law 59.4% Spouse 12% Other relative 21.5% Non relative 7% Significantly higher (p<0.05) difficulty than non-dementia caregivers "creates or aggravates health problems"	(none)	(none)	(none)	Demo-graphics
30.	Cheah, W. K., Han, H. C., Chong, M. S., Anthony, P. V., & Lim, W. S. (2012).	Outcome: Worry about own performance as a caregiver was the highest factor endorsed at every stage from MCI to Severe at	Zarit	(none)	(none)	Dementia

	Multidimensionality of the Zarit Burden Interview actors the severity spectrum of cognitive impairment: An Asian perspective. *International Psychogeriatrics, 24*(11), 1846–1854.	significant levels. It was generally rated higher by caregivers who were not currently living with the care recipient. - Role strain became more dominant as ADL's worsened. - Personal strain was consistent across severity.				
31.	Chou, K. R., LaMontagne, L. L., & Hepworth, J. T. (1999). Burden experienced by caregivers of relatives with dementia in Taiwan. *Nursing Research, 48*(4), 206–214.	Taiwan study. Outcome: Lower caregiver burden assoc. with higher caregiving self-efficacy and problem focused coping. Psychological and physical demands of care do not directly impact caregiver burden BUT they both contribute to caregiver involvement. Higher caregiver involvement and higher emotion focused coping lead to increases in caregiver burden.	CBI	Ways of Coping Questionnaire	(none)	Dementia
32.	Coen, R. G., Swanwick, G. R. J., O'Boyle, C. A., Coakley, D. (1997). Behaviour disturbance and other predictors of carer burden in Alzheimer's disease. *International Journal of Geriatric Psychiatry, 12*, 331–336.	Outcome: MMSE score had no association with burden score ADL/IADL score had no association with burden score Behavioural disturbance had positive correlation with burden score Informal social support score had negative correlation with burden score Support group interventions were more effective when they targeted carer's reaction to behavioural disturbances in care recipient	Zarit	Social Support Behaviour Scale	(none)	Dementia Recommendations
33.	Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry, 17*, 184–188.	Aspects of caregiving that are rated as positive: - Companionship (22.5%) - sense of it being fulfilling/rewarding (21.8%) - sense of duty and obligation (10.4%) - enjoyment (12.8%) Caregivers who reported more +ve aspect reported	Zarit	(none)	CES-D	Recommendations Dementia

		lower depression, ZBI, or poor health				
34.	Cole, J. D. & Kazarian, S. S. (1993). Predictive validity of the Level of Expressed Emotion (LEE) Scale: Readmission follow-up data for 1, 2, and 5-year periods. *Journal of Clinical Psychology, 49*(2), 216–218.	Schizophrenia patients were at highest risk for rehospitalization at 2- and 5-year follow ups. The high LEE group was 3 to 5 times more likely to be hospitalized after 5 years than the low LEE group. Mean scores of patients rehospitalized within 2 years = 20.7 Mean scores of patients not rehospitalized after 2 years = 11.5	(none)	LEE	(none)	Schizo-phrenia
35.	Cooper, C., Owens, C. Katona, C., & Livingston, G. (2008). Attachment style and anxiety in carers of people with Alzheimer's disease: Results from the LASER-AD study. *International Psychogeriatrics, 20*(3), 494–507.	Outcome: Carers with poor attachment style and/or dysfunctional coping respond to caring responsibilities with more anxiety regardless of caree's ADL score. -Depression correlated with carer avoidant attachment style. -Carer's burden rating did not correlate with attachment style. -Problem focused strategies by caregivers led to higher anxiety in caregiver after 1 year. Emotion focused strategies led to lower anxiety (i.e., acceptance, comfort from others, humour, positive reframing, and religion).	Zarit (same subjects as other Cooper article – used these results)	Brief COPE	Hospital Anxiety and Depression Scale (HADS)	Dementia
36.	Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23*, 929–936.	Outcome: caregivers with avoidant/ambivalent attachment style (are reluctant to get close to others for fear their feelings won't be reciprocated) report more anxiety than caregivers with an anxious attachment style (fear of abandonment) regardless of burden.	Zarit (same subjects as other Cooper article – did not use these results)	Brief COPE	HADS	Dementia
37.	Crawford, J. R., Henry, J. D., Crombie, C., & Taylor, E. P. (2001).	HADS Anxiety mean 6.14, sd 3.76 Depression mean 3.68, sd 3.07	(none)	(none)	(none)	(none)

	Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology, 40*, 429–434.	Percentages of total sample classified as mild 20.6%, moderate 10%, and severe 2.6%				
38.	Cutrino, A. & Santamaria, J. (2013). Research on family caregivers: Understanding levels of burden and how to provide assistance. *Home Healthcare Nurse, 31*(6), 331–337.	Recapitulates four studies: O'Leary 2010, Limpawattana 2013, Elliott 2010, and Brodaty 2012	(none)	(none)	(none)	Older Adults
39.	Daigneault, P.-M., Jabob, S. & Ouimet, M. (2012). Using systematic review methods within a Ph.D. dissertation in political science: Challenges and lessons learned from practice. *International Journal of Social Research Methodology, 17*(3), 267–283.	Difference between systematic review and lit review is that syst rev conforms to methodological standards of research including reproducibility and transparency whereas lit rev can be skewed toward unrepresentative samples that tell the story the researcher wants to tell. Quote from Denyer & Tranfield 2009 p. 672 : It is a specific methodology that locates existing studies, selects and evaluates contributions, analyzes and synthesizes data & reports the evidence in such a way that allows reasonably clear conclusions to be reached about what is and is not known" (epistemology: how do we know what we know? Distinguishes justified belief from opinion.) Stages of Syst Rev 1) Specify a question 2) Identify references 3) Select relevant references 4) Assess study quality	(none)	(none)	(none)	System-atic review method-ology

		5) Data extraction 6) Data synthesis				
40.	Dellesega, C. (1991). Caregiving stress among community caregivers for the elderly: Does institutionalization make a difference? *Journal of Community Health Nursing, 8*(4), 197–205.	-No significant change in mean burden score between active caregivers and nonactive caregiver (re: care recipient placement in skilled nursing facility) possibly because choice to place and placement transition highly stressful events. -No significant change in subscale personal strain -No significant change in subscale physical role strain, possibly because a) many people continue to visit facility daily for hands-on assistance in care, and b) travel to/from facility regularly creates new burdens on caregivers.	Zarit	(none)	(none)	Dementia
41.	De Leo, D., Frisone, G. B., Rozzini, R. & Trabucchi, M. (1993). Italian community norms for the Brief Symptom Inventory in the elderly. *British Journal of Clinical Psychology, 32*, 209–213.	-sample aged 75+, *n* = 462, MMSE >18, from 2 communities in Northern Italy. -165 male, 297 female -BSI with 9 scales plus GSI, 49-items Depression subscale Total 0.60 sd .65 Males 0.41 sd .53 Females 0.70 sd .69	(none)	(none)	BSI	Elderly
42.	Derogatis, (1993). *Brief Symptom Inventory.* San Antonio, TX: Pearson.	BSI instrument and manual Community sample t-score cutoff for significant distress = 63 on subscale score	(none)	(none)	BSI	General population
43.	Dow, B., Moore, K., Scott, P., Ratnayeke, A., Wise, K., Sims, J., & Hill, K. (2008). Rural carers online: A feasability study. *Australian Journal of Rural Health, 16*, 221–225.	Outcome: computer installation and training sessions for older carers living in remote areas of Australia showed that increased connection to children and grandchildren by email, connections with friends and neighbours by email, and increased confidence for using computer and internet resulted in decreases in loneliness for 11/14 and depressive sx for 9/14 participants but no significant change in reported burden.	Zarit	(none)	GDS 15 UCLA Loneliness	Frail elderly

44.	Elliott, A. F., Burgio, L. D., & DeCoster, J. (2010). Enhancing caregiver health: Findings from the Resources for Enhancing Alzheimer Caregiver Health II intervention. *American Geriatrics Society, 58*(1), 30–37.	REACH (Resources for Enhancing Alzheimer Caregiver Health) established in 1995. -control group mailed packet of educ materials and 2 brief check in phone calls at 3 & 5 mos. -intervention group over 6 months rec'd 9 in-home visits and 3 phone sessions with interventionist to target mood (depression), burden, and physical health. -Mood: education about importance of pleasant activities and emotional wellbeing, teaching & practicing strategies for engaging in pleasant events, role play for mood mgmt and using thought record, scheduling pleasant events. -Burden: educ material on safety caregiving and stress, practice breathing, music & stretching exercises, referral for stress mgmt feature on computerized phone system. -Physical health: educ material on self care & preventive health practices, reviewing personalized health record, teaching nutrition, ways to remember medical appts, & adhering to meds schedule, referral to healthy living feature on computerized phone system. Outcome: significant improvement in self rated health, mood & physical. Below significant improvement in sleep. Recommended one-on-one caregiver coaches for individualized support/interventions	Zarit	(none)	CES-D (Use baseline scores)	Dementia Recom-mendations
45.	Fearon, M., Donaldson, C., Burns, A. & Tarrier, N. (1998). Intimacy as a determinant of expressed emotion in carers of people with Alzheimer's disease.	Hypothesis that high critical and hostile EE attitudes/remarks are the result of problems in the interpersonal relationship between the carer and care recipient (based on theory by Gilhooly and Whittick, 1989), therefore the couple's current level of affection and capacity for	(none)	Camberwell CFI (use data from current intimacy only)	(none)	Dementia

	Psychological Medicine, 28, 1085–1090.	conflict resolution are good predictions of EE in carer -Outcome: as dementia progresses the level of intimacy between carer and care recipient diminishes irrespective of previous level of intimacy. -high intimacy significantly related to low EE in both past and present conditions -low intimacy significantly related to high EE in both past and present conditions -Poor current relationship a better predictor of current EE than past relationship; maybe due to recollection bias -Previous high intimacy not apparently protective against current EE when current relationship quality is poor. -poor past relationship resulting in current high EE probably because the absence of past reciprocity, longstanding unresolved interpersonal problems reactivated when must spend more time together. -current poor relationship may be due to memory loss in dementia causing care recipient to be unable to share thoughts and feelings so carer feels unloved				
46.	Federal Interagency Forum on Aging-Related Statistics (2012). *Older Americans 2012: Key Indicators of Well-Being.* Washington, DC: U.S. Government Printing Office.	www.agingstats.gov/againgstatsdotnet/main_site/data/2012_documents/docs/entirechartbook.pdf - in USA 2010 population of 65+ years old = 40 million (13% of population) - 85+ years old = 5.5 million - based on 2000 census project to increase so that by 2030 72 million will be over 65 (20% of popln) - projected 19 million 85+ year olds by 2050 - in 2009, 41% of 65+ year olds reported functional limitations; 12% reported at least 1 ADL difficulty; 25 % reported >1 ADL difficulty; 4% reported living in long term care facility	(none)	(none)	(none)	Demographics

		-in 1992, 6% were living in LTC facility, possible the decrease to 4% is due to more unpaid informal caregivers (source: Medicare enrollees)				
47.	Ferri, C. P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., . . . Alzheimer's Disease International (2005). Global prevalence of dementia: A Delphi consensus study. *Lancet, 366*(9503), 2112–2117.	Delphi study to determine global prevalence of dementia. Estimated 2001 worldwide dementia is 24.3 million. Projected to double every 20 years therefore 42.3 million in 2020 and 81.1 million in 2040. - 60.1% of dementia cases live in developing countries. - highest in 2001 = China (5 million), EU (5 million), USA 2.9 million, India (1.5 million), Japan (1.1 million), Russia (1.1 million), Indonesia (1.0 million). - Latin America currently has estimated 1.8 million, North America 3.4 million but projected by 2040 people with dementia will be Latin Am 9.1 million, North Am 9.4 million	(none)	(none)	(none)	Demo-graphics Dementia
48.	Fingerman, K. L. (1996). Internal resourcefulness, task demands, coping, and dysphoric affect among caregivers of the frail elderly. *International Journal of Aging and Human Development, 42*(3), 229–248.	Hypothesis that situation of longterm caregiving is consistent with learned helplessness paradigm therefore higher perceived internal resourcefulness of caregiver will correlate with lower scores on scale measuring depression. Outcome: supports hypothesis	(n/a)	Indices of Coping (IC)	BDI HADS	Frail Elderly
49.	Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behaviour, 21*, 219–239.	Initial development of Ways of Coping checklist. 68 items. Based on analytical defensive coping mechanisms (avoidance, intellectualization, isolation, suppression) plus Information-seeking, Problem-solving, Palliation; Inhibition of action, Direct action, & Magical thinking. Split checklist into 2 categories: Problem focused (cognitive and behavioural strategies for	(none)	WCCL	(none)	General Popula-tion

		managing source of problem) Emotion focused (cognitive and behavioural strategies for managing emotional distress) Most participants reported using both types of coping for a single stressful event so looked at "coping patterns" to see which category each individual used proportionately more than the other.				
50.	Folkman S. & Lazarus, R. S. (1988). Coping as a mediator of emotion. Journal of *Personality and Social Psychology, 54*(3), 466–475.	Ways of Coping checklist with 8 forms of coping that are split into 3 categories: 1) Emotion-focused strategies. Includes self-control, accepting responsibility, positive reappraisal, and seeking social support. 2) Problem-focused strategies. Includes planful problem solving and seeking social support. 3) Dysfunctional strategies. Includes ineffective emotion- or problem-focused strategies such as escape-avoidance, distancing, and confrontive coping (i.e., expressing hostility). Any stressful event has multiple impacts on wellbeing and may lead to conflicting emotions. Appraising the event and behavioural options (acts and thoughts) can lead to change in emotions and the appraisal is therefore "coping" and mediates the emotional response. Confrontive Coping = expressing anger and hostility, e.g. "Getting it off your chest makes you feel better"; tends to be related to more depressive sx. Distancing = "didn't let it get to me", "refused to think too much about it", went on as if nothing had happened" led to worsened emotional state Planful problem solving = reduced negative emotions, higher positive emotions "I	(none)	WCCL	(none)	General Population

		made a plan of action and followed it"				
51.	Garcia-Alberca, J. M., Lara, J. P., Garrido, V., Gris, E., González-Herero, V., & Lara, A. (2014). Neuropsychiatric symptoms in patients with Alzheimer's disease: The role of caregiver burden and coping strategies. American *Journal of Alzheimer's Disease & Other Dementias, 29*(4), 354–361.	Outcome: Caregivers who use disengagement strategies to cope with care recipients also report higher burden and rated neuropsych sxs in care recipient higher. Disengagement strategies incl. avoiding thinking/doing anything abt the sitn, go along as if nothing were happening; hoping a miracle would happen, wish sitn would go away; self criticism, self blame; spent more time alone, avoided people. Engagement = worked on problem solving, followed a plan; looked at sitn differently in a more positive light, convinced self it wasn't so bad; let emotions out, let go of emotions ; talked to someone abt feelings, found good listener.	CBI	(none)	BDI	Dementia
52.	Gaugler, J. E., Mittelman, M. S., Hepburn, K., & Newcomer, R. (2010). Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. *BMC Medicine, 8*(85). doi:10.1186/1741-7015-8-85	Outcome: Overall, burden scores decreased significantly 6- and 12-months after nursing home placement compared to pre-placement. Overall, depression symptoms showed less pronounced post-placement reduction but still significant. Note: Caregivers who did not show decreased burden were wives (8.84x more likely to experience high burden than others at 6-months and 29.16x more likely at 12-months) and daughters (2.75 and 3.89 times more likely to experience high burden than others) of care recipient. Caregivers who did not show decreased depression were husbands of care recipient (4.87 and 5.89 times more likely to experience depression than others).	Zarit (use baseline scores)	(none)	GDS (use baseline scores)	Dementia
53.	Gilhooly, M. L. M., & Whittick, J. E. (1989). Expressed emotion in	Did not used standardized instrument but based interview on Camberwell Family Interview and counted # critical/hostile	(none)	Semi-CFI	(none)	Dementia

	caregivers of the dementing elderly. *British Journal of Medical Psychology, 62*, 265–272.	comments. Seemingly this is the first study to examine EE in caregivers of people with dementia. Outcome: Higher critical comments signif correl with lower caregiver morale and poorer caregiver mental health. Females more critical than males. Poor quality of past relationship predicts higher critical comments.				
54.	Hale, W. D., Cochran, C. D., & Hedgepeth, B. E. (1984). Norms for the elderly on the Brief Symptom Inventory. *Journal of Consulting and Clinical Psychology, 52*(2), 321–322.	BSI is an abbreviated from of the SCL-90. 364 female and 201 male age 60+ to determine norms for older adults. Depression subscale Males young adult M.28 SD.31 (Derogatis sample) older adults M.43 SD.5 Depression subscale Females young adult M.46 SD.52 (Derogatis sample) older adults M.53 SD.59	(none)	(none)	SCL-90 BSI	Normative population
55.	Hanson, C. D. & Clarke, C. (2013). Is expressed emotion related to estimates of ability made by older people with cognitive impairments and their partners? *Aging and Mental Health, 17*, 535–543.	Outcome: no diff btwn high and low EE groups for discrepancy between patient's and partner's ratings of patient's IADLs -signif diff btwn between patient's and partner's ratings of patient's cognitive decline. Suggests that higher criticism and/or EOI from caregiver is related to greater disagreement between pt and caregiver about severity of cognitive impairments	(none)	FMSS	GHQ-12	MCI & Dementia
56.	Hébert, R., Bravo, G., & Préville, M. (2000). Reliability, validity and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia.	Data collected from Canadian Study of Health and Aging to establish reference values for low, moderate, high, severe burden. Recommended that median values are more accurate descriptors due to influence on outliers on mean.	Zarit	(none)	(none)	Dementia

	Canadian Journal on Aging, 19(4), 494–507.					
57.	Heru, A. M., Ryan, C. E., & Iqbal, A. (20014). Family functioning in the caregivers of patients with dementia. *International Journal of Geriatric Psychiatry, 19*, 533–537.	Caregivers reported quality of life as similar compared to control group. Ratings on family functioning predicted caregivers' experience of strain in caregiving role. 64% reported good family functioning, 36% reported poor family fn. Rewarding aspects of caregiving included "feeling needed and responsible" "doing for someone what you want for yourself and knowing I've done my best" "being able to help" "I feel that she is loved and not alone"	(none)	(none)	(none)	Dementia
58.	Hinrichsen, G. A., & Niederehe, G. (1994). Dementia management strategies and adjustment of family members of older patients. *Gerontologist, 34*(1), 95–102.	- Criticism describes efforts to manage the person by yelling, criticizing, threatening and related behaviours. - Encouragement includes efforts to praise the person, get him or her to discuss feelings or look on the bright side of things, and similar efforts. - Active management includes activities to safeguard, assist, engage, stimulate, and monitor and associated behaviours primarily directed towards modifying the environment or daily routine. Outcome – Avoidance coping strongly related to criticism - Criticism associated with higher burden, more psych sx, and greater desire to institutionalize the patient - Encouragement associated with less burden, less desire to institutionalize the pt - Active mgmt assoc w more burden and greater desire to institutionalize the pt -Active Cognitive Coping (changing own attitude toward the stressor) assoc w less burden -Active behavioural coping (taking positive action to	Zarit	Dementia Management Strategies Scale (DMSS)	SCL-90	Dementia

		address the stressors) assoc w more burden				
59.	Hinrichsen, G. A., Adelstein, L., & McMeniman, M. (2004). Expressed emotion in family members of depressed older adults. *Aging and Mental Health, 8*(4), 355–363.	Review of EE in caregivers of dementia summarizes no relationship to Demographics or illness characteristics of patient but there is relationship btwn high EE and caregiver emotional distress. Current study: 61+ y.o. patients hospitalized for depression, spouses & adult children given CFI. Mean critical remarks in 1st hour = 4.54 (SD 4.53). Mean Hostility behaviours 0.15 (SD .36). Mean Warmth remarks 2.46 (SD 1.29). Mean Emotional overinvolvement behaviours 1.83 (SD 0.44).	Zarit	Camberwell CFI	BDI-II	Older Adults with Depression
60.	Hirakawa, Y., Kuzuya, M., Enoki, H., Hasegawa, J., & Iguch, A. (2008). Caregiver burden among Japanese informal caregivers of cognitively impaired elderly in community settings. *Archives of Gerontology and Geriatrics, 46*, 367–374.	Purpose of study to examine dementia caregiver burden in central Japan. Control group, mild dementia group, severe dementia group. Outcome: Japan provides in-home physician and nurse visits and 90% of caregivers endorsed using formal care while caregiving at home. In sum, there were no significant differences in level of caregiver burden between mild and severe dementia of patients.	Zarit	(none)	(none)	Dementia
61.	Hirano, A., Suzuki, Y., Kuzuya, M., Onishi, J., Ban, N., & Umegaki, H. (2011). Influence of regular exercise on subjective sense of burden and physical symptoms in community-dwelling caregivers of dementia patients: A randomized controlled trial. *Archives of Gerontology*	Outcome: exercise intervention reduced burden scores significantly. - exercise intervention improved quality of sleep scores significantly	Zarit	(none)	VAS	Dementia Recommendations

	and Geriatrics, 53, e158–e163.					
62.	Hooley, J. M., & Gotlib, I. H. (2000). A diathesis-stress conceptualization of expressed emotion with clinical outcome. *Applied and Preventive Psychology, 9*, 135–151.	Looks at interactions between vulnerability and psychosocial stressor that result in psychiatric relapse. -Critical remarks: reflect dislike or disapproval of something the pt does -Hostility: criticize pt for who s/he is rather than specific behaviours (e.g. she's a bad egg) -EOI: dramatic, overprotective, devoted or self-sacrificing response to the pt's illness that is out of proportion to the circumstances -Personalities of high EE ppl less flexible and less tolerant, more self-critical, more internally based locus of control than low EE ppl -re: ppl with internal locus of control tend to believe the pt could do more to control sx; external locus of control tend to view pt's problems as universal to the dx and uncontrollable by the pt. -diathesis means predisposition/vulnerability -"criticism is a tangible expression of a wish for a person to behave differently" -high EE more critical of behavioural deficits or breaking social norms than of positive sx -high EE try to influence pt's behaviour using controlling speech that often leads to escalating negative verbal and nonverbal exchanges that are stressful to the family and result in autonomic system response in vulnerable patients, possibly prompting increased sx -Tx recommendation to increase relatives' acceptance of the dx and circumstance	(none)	(none)	(none)	Depression Borderline Schizophrenia
63.	Hooley, J. M. & Parker, H. A. (2006). Measuring	EE measures quality of patient-relative relationship. High EE is related to reciprocal negativity	(none)	CFI FMSS LEE FAS	(none)	Families

	expressed emotion: An evaluation of the shortcuts. *Journal of Family Psychology, 20*(3), 386–396.	between them and predicts sx relapse. Family-based interventions targeting reduction of EE decrease sx relapse rate. CFI gold standard (standardized interview, 1-2 hours to admin, 2-3 hours to code, 40-80 hours training) Five Minute Speech Sample FMSS (standardized interview, 5 mins admin, 20 mins code) Level of Expressed Emotion Scale LEE (60 item self report) Family Attitude Scale FAS (30 item self report) Perceived Criticism PC (interview or self report, 2 questions on 10 pt likert scale, 2 qualitative questions)		PC		Recommendations
64.	Hooley, J. M. (2007). Expressed emotion and relapse of psychopathlogy. *Annual Review of Clinical Psychology, 3*, 329–352.	-children at genetic risk of developing schizophrenia signif more likely to develop it when adopted into high EE family; children with no genetic risk will <u>not</u> develop schizophrenia if adopted into high EE family - higher EE in family members of pt's showing more aggressive or delinquent beh and pt's who do not have outside work/hobbies; also higher EE in families who reported better premorbid functioning of pt -EE levels are fluid, can change over time and depending on level of pt's sx -Across cultures, a handful of studies show lower EE in India than US and UK, lower EE in Latino than non-Latino, lower EE in British Sikh or white than British Pakistani (study notes that EE includes EOI) In Japan high EOI more predictive of relapse whereas in India high hostility more related to relapse, in Egypt less relapse with criticism than in western countries	(none)	(none)	(none)	Schizophrenia Mood d/o Anxiety d/o Eating d/o Substance Use d/o Personality d/o Multicultural measures of EE

65.	Huang, M.-F., Huang, W.-H., Su, Y.-C., Hou, S.-Y., Chen, H.-M., Yeh, Y.-C., & Chen, C.-S. (2013). Coping Strategy and Caregiver Burden Among Caregivers of Patients With Dementia. *American Journal of Alzheimer's Disease and Other Dementias, 28*(4).	Outcome – caregivers tended to use avoidance coping strategy (distracting attention to avoid thinking about sitn) when faced with pt's depressive and disruptive sx - caregivers tended to use wishful thinking coping strategy (imagining sitn is not as bad or is only temporary) to address pt's depressive sx - avoidance related to higher burden scores, higher depressive sx in caregiver, and lower life satisfaction - no significant relation btwn burden and problem solving coping strategy	CBI	WCCL-R	(none)	Dementia
66.	Joling, K. J., van Hout, H. P. J., Schellevis, F. G., van der Horst, H. E., Scheltens, P., Knol, K. L., & van Marwijk, H. W. J. (2010). Incidence of depression and anxiety in the spouses of patients with dementia: A naturalistic cohort study of recorded morbidity with at 6-year follow-up. *American Journal of Geriatric Psychiatry, 18*(2), 146–153.	Netherlands medical records 2001-2007 Outcome: spouses of pt with dementia have 4x risk of having a depression dx than spouses of nondementia people	(none)	(none)	DSM-IV criteria	Dementia
67.	Joling, K. J., van Marwijk, H. W., Veldhuijzen, A. E., van der Horst, H. E., Scheltens, P., Smit, F., & van Hout H. P. (2015). The two-year incidence of depression and anxiety disorders in spousal caregivers of	In Netherlands depr and anxiety measured every 3 mos in caregivers of ppl w dementia with no d/o at baseline. Outcome: 60% of caregivers developed DSM-IV clinical depression or anxiety within 24 months of care recipient dx with dementia. Highest predictors were caregivers' preexisting subclinical anxiety or depression.	(none)	(none)	(none)	Dementia

	persons with dementia: Who is at the greatest risk? *American Journal of Geriatric Psychiatry, 23*(3), 293–303. doi: 10.1016/j.jagp.2014.05.005.					
68.	Kessler, R. C., Chiu, W. T., Demler, O., & Walters, E. E. (2005). Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey replication. *Archives of General Psychiatry, 62*(6), 617–627.	US English speaking 18 yrs+ population *n* = 9,282 Prevalence MDD 6.7% Prevalence Dysthymia 1.5%	(none)	(none)	(none)	Demo-graphics
69.	Leff, J., Kuipers, L., Berkowitz, R., & Sturgeon, D. (1985). A controlled trial of social intervention in the families of schizophrenic patients: Two year follow-up. *British Journal of Psychiatry, 146,* 594–600.	Control group families given no follow up after psych hospital discharge of patient with schizophrenia resumed living at home and using antipsychotic medication. Experimental group families received psychoeducation about course and mgmt of schizoph, participation in support group with other relatives of schizoph patients, and in-home family therapy sessions directed at reducing EE and reducing face-to-face contact btwn pt and high EE family member. Outcome: At 9 mos no rehospitalizations in experimental grp but 50% of control grp rehospitalized. At 2 yrs, relapse was 14% in exp grp and 78% in control grp.	(none)	Camberwell	(none)	Schizo-phrenia
70.	Leff J. P., & Vaughn C. (1985). *Expressed emotion in Families: Its significance for*	Description of the EE scales and how they were developed. Instructions on how to rate the 5 scales.	(none)	Camberwell	(none)	Schizo-phrenia

	mental illness. New York, NY: Guilford.					
71.	Leggett, A. N., Zarit, S., Taylor, A., & Galvin, J. E. (2010). Stress and burden among caregivers of patients with Lewy Body Dementia. *Gerontologist, 51*(1), 76–85.	Outcome: worry about performance was the most strongly endorsed item by LBD caregivers	Zarit	(none)	(none)	Dementia
72.	Lewinsohn, P. M., Seeley, J. R., Roberts, R. E., & Allen, N. B. (1997). Center for Epidemiologic Studies Depression Scale (CES-D) as a screening instrument for depression among community-residing older adults. *Psychology and Aging, 12*(2), 277287.	established norms for older adults aged 50+ with a mean of 8.33 (SD 6.84). *n* = 1005 ppl age 50-96	(none)	(none)	CES-D	Older Adults
73.	Li, C.-Y., & Lewis, F. M. (2013). Expressed emotion and depression in caregivers of older adults with dementia: Results from Taiwan. *Aging and Mental Health, 17*(8), 924–929.	Outcome: significant finding that the higher the EE, the higher the depressed mood and burden and the lower the caregiver perceived his/her health. Low educ and income assoc w high EE	Zarit	Level of Expressed Emotion (LEE)	CES-D	Dementia
74.	Li, C.-Y., & Murray, M. A. (2014). A review of conceptualization of expressed emotion in caregivers of older adults with dementia. Journal of Clinical Nursing. doi:	Review of primary studies in dementia with expressed emotion. Cross studies comparisons difficult because investigators are using different cut-off rates to determine significance. English and Chinese studies included.	(none)	(none)	(none)	Dementia

	10.1111/jocn.12619.					
75.	Liew, T. M., Luo, N., Ng, W. Y., Chionh, H. L., Goh, J., & Yap, P. (2010). Predicting gains in dementia caregiving. *Dementia and Geriatric Cognitive Disorders, 29*, 115–122.	Caregiver gain = positive outcomes experienced in caregiving such as personal growth (patience, self awareness, sense of competence, knowledge), improved relationships (with caree, family members, older people in general), spiritual growth (change in life philosophy, altruism) - caregivers who endorse less mental distress, use active management style, and participate in educational and support group programs also endorse significantly more gains from caregiving. - criticism correlates negatively with gain - encouraging the care recipient correlates positively with gain - active management = efforts to safeguard, assist, engage, stimulate, monitor, modify the environment and daily routine of care recipient.	Zarit	DMSS	GHQ-28	Dementia
76.	Lim, J., Griva, K., Goh, J., Chionh, H. L., & Yap, P. (2011). Coping strategies influence caregiver outcomes among Asian family caregivers of persons with dementia in Singapore. *Alzheimer's Disease and Associated Disorders, 25*(1), 34–41.	English and Mandarin versions option. Transactional model of stress and coping = people experience more distress in the face of adversity if they believe they do not have sufficient internal or external coping resources Outcome: Use of behavioural disengagement and criticism as coping strategies significantly predicted higher caregiver's burden level regardless of pt's severity of sx Use of encouragement with care recipient correlated with caregiver gain	Zarit	Brief COPE DMSS	(none)	Dementia
77.	Lyness, J. M., Noel, T. K., Cox, C., King, D. A., Conwell, Y., & Caine, E. D. (1997). Screening for depression in elderly primary care patients. A	established optimum cutoff scores for recognizing major depressive disorder in older patient samples as 21. *n* = 30 ppl age 60+	(none)	(none)	CES-D	Older Adults

	comparison of the Center for Epidemiologic Studies-Depression Scale and the Geriatric Depression Scale. Archives of Internal Medicine, 157(4), 449–454.					
78.	Magai, C., & Cohen, C. I. (1998). Attachment style and emotion regulation in dementia patients and their relation to caregiver burden. *Journal of Gerontology, 53*B, P147–P154.	Outcome: Caregiver burden was signif higher for insecurely attached patients; i.e. avoidant individuals with basic mistrust, inhibition and high hostility, and ambivalent individuals with anxiety and sadness - 80% of participants African American	Zarit	(none)	(none)	Dementia
79.	Mausbach, B. T., Chattillion, E. A., Roepke, S. K., Patterson, T. L., & Grant, I. (2013). A comparison of psychosocial outcomes in elderly Alzheimer caregivers and noncaregivers. *American Journal of Geriatric Psychiatry, 21*(1), 5–13.	Compares 125 AD caregiver spouses to 60 spouses of non-AD people of similar age 40 of AD caregivers meet depression criteria 5% of non-AD spouses meet depr criteria	(none)	(none)	(none)	Demo-graphics
80.	McConaghy, R., & Caltabiano, M. L. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health*	Outcome – carer satisfaction with life not correlated with levels of reported depression but is strongly correlated with levels of burden - significant correl between high burden and poor psychological health - no relationship between forms of coping and physical health but a strong correlation between low levels of well being and high levels of burden.	Zarit	COPE	CES-D	Dementia

	Science, 7, 81–91.	- no difference btwn males and females on emotional coping or life satisfaction - burden not associated with length of time caring but longer duration of care is associated with higher levels of well-being - no difference in life satisfaction between older and younger caregivers				
81.	McCurry, S. M., Vitiello, M. V., Gibbons, L. E., Logsdon, R. G., & Teri, L. (2006). Factors associated with caregiver reports of sleep disturbances in persons with dementia. *American Journal of Geriatric Psychiatry, 14*(2), 112–120.	Almost ½ of patients whose caregivers reported they were having multiple sleep disturbances weekly were actually sleeping well (8-9 hours per night). Patients who have better sleep than their caretakers rate them as having are associated with caregiver tendency to use high criticism. Clinicians must be careful to understand the nature of the sleep disturbance reports prior to prescribing pharmacologic tx.	(none)	Brief COPE	GDS	Dementia
82.	McLennon, S. M., Habermann, B., & Rice, M. (2011). Finding meaning as a mediator of burden on the health of caregivers of spouses with dementia. *Aging and Mental Health, 15*(4), 522–530.	Finding meaning = cognitive transformative process that changes a stressful situation into a useful experience that leaves one with a broader perspective on life Outcome – positive aspects of caregiving, such as finding meaning, is negatively correlated with caregiver burden and positively associated with mental health	Zarit	(none)	Short Form Health Survey-36 Version 2	Dementia
83.	Meyer, B. (2001). Coping with severe mental illness: Relations of the Brief COPE with symptoms, functioning, and well-being. *Journal of Psychopathology and Behavioral Assessment, 23* (4), 265–277.	States that direct correspondence with Carver indicates there are no published norms for the Brief COPE.	n/a	Brief COPE	n/a	Psychiatric inpatients
84.	Miller, E. A., Rosenheck, R. A., & Schneider,	Outcome: Higher caregiver burden ratings are positively related to higher	Zarit	(none)	BDI	Dementia

	L. S. (2010). Caregiver burden, health utilities, and institutional service costs among community-dwelling patients with Alzheimer disease. *Alzheimer's Disease and Associated Disorders, 24*, 380–389.	costs of institutional service (inpatient hospital, medical visits, nursing home, residential care) use regardless of physical health of patient. Factors such as caregiver depression, distress and time commitments.				
85.	Montero, I., Asencio, A., Hernández, I., Masanet, M. J., Lacruz, M., Bellver, F., Iborra, M., & Ruiz, I. (2001). Two strategies for family intervention in schizophrenia: A randomized trial in a Mediterranean environment. *Schizophrenia Bulletin, 27*(4), 661–670.	Relatives of patients with schizophrenia in Spain. Behavioural intervention with family unit including patient done in the home psychoeducation, communications skill straining, practice of family problem solving techniques. vs. Expressed emotion family therapy without patient present. Psychoeducation, problem solving skills training, reduce criticism and overinvolvement interventions, expand social networks interventions, lower expectations intervention. Outcome: no signif diff between groups in relapse rate for patients at 8 months post tx. Whole family behavioural intervention outcome patients mean meds dosage signif lower than EE intervention group.	(none)	CFI	GHQ	Schizophrenia
86.	Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., & Ustun, B. (2007). Depression, chronic diseases, and decrements in health: Results from the World Health Surveys. *Lancet,*	Adults over 18 with ICD-10 dx of Single depressive episode = 3.2% *n* = 245,404 60 countries	(none)	(none)	(none)	Demographics

	370(9590), 851–858.					
87.	National Alliance for Caregiving & AARP, Inc. (2009). *Caregiving in the U.S.* Retrieved from http://www.aarp.org/caregivingus	Whereas 13% of popln reports physical health as fair or poor, 17% of caregivers report fair/poor, and when been providing care 5+ years, 23% report fair/poor. Coordinating paid services increases caregiver burden (20% report high burden when not coordinating care vs 32 % report high burden when also coordinating care. Co-residence and high burden rating are related to high emotionally stressful rating. Especially ratings that caregiving takes time away from friends/other family members are more likely to rate emotional stress as high (47% compared to only 14% who endorsed less impact on other relationships) Since 2008, 15% rate caregiving as source of high degree of financial hardship.	(none)	(none)	(none)	Demographics
88.	Nomura, H., Inoue, S., Kamimura, N., Shimodera, S., Mino, Y., Gregg, L., & Tarrier, N. (2005). A cross-cultural study on expressed emotion in carers of people with dementia and schizophrenia: Japan and England. *Social Psychiatry and Psychiatric Epidemiology, 40*, 564–570.	Compared EE and burden among 4 groups: Japanese with dementia, Japanese with schizophrenia, English with dementia, English with schizophrenia. Outcome: Japanese carers expressed fewer positive and negative emotional responses therefore cutoffs may need to be lower for patients from Eastern cultures	Zarit	Camberwell CFI	BDI GHQ	Dementia
89.	Novak, M. & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. *Gerontologist, 29*(6), 798–803.	Caregiver Burden Inventory Scales: 1) Time Dependence: measures time spent performing ADLs and increased time spent on vigilance 2) Developmental: measures stage of life being disrupted; i.e., not what	CBI	(none)	(none)	General Population

		expected life to be at this age/stage 3) Physical: measures chronic fatigue and higher risk of physical illness 4) Social: measures feeling unappreciated or neglected, as well as conflict with other family members over how to manage the care 5) Emotional: measures shame, embarrassment, resentfulness, anger related to the care receiver				
90.	Okamoto, K., Momose, Y., Fujino, A., & Osawa, Y. (2009). Life worth living for caregiving and caregiver burden among Japanese caregivers of the disabled elderly in Japan. *Archives of Gerontology and Geriatrics, 48,* 10–13.	Life worth living was assessed by one question: “How much do you feel the sense of life worth living for nursing care at home?” Outcome: caregivers who rated high burden on an Arai et al (2001) created scale significantly reported less life worth living (p = 0.0001).	(none)	(none)	(none)	Frail elderly
91.	Orford, J., O’Reilly, P., & Goontilleke, A. (1987). Expressed emotion and perceived family interaction in the key relatives of elderly patients with dementia. *Psychological Medicine, 17*(4), 963–970.	Caregivers of ppl w dementia compared w caregivers of ppl with schizophrenia, elderly psychiatric pts, and physically ill elderly pts. Outcome: Caregivers of ppl w dementia were more dominant (control, put down, bossy towards, don’t let person be him/herself), more protective (tell what to do, pamper, calm, help, take care of, protect), and less submissive (follow lead, want to be led by, do what tells, dependent on, meek with, accept what said, cling to, give in to) toward care recipient than other caregiver groups. Possibly as result of controlling/protecting inherent in dementia caregiver role, most family report loss in affection and increase in hostile interactions. Perceive the loss of affection as mutual and perceive self as more hostile than care recipient.	(none)	Camberwell Family Interview	(none)	Dementia

		Outcome: in terms of EE, no signif diff btwn dementia caregivers and other groups.				
92.	Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with Alzheimer's disease and related dementias. *Gerontologist, 47*(6), 798–809.	- Grief def'n: the reaction to the perception of loss with normative symptoms incl yearning, sadness, anger, guild, regret, anxiety, loneliness, fatigue, shock, numbness, positive feelings, and physical sx. -In dementia, loved ones experience grief related to loss of quality of the relationship, loss of established roles in the relationship, loss of control, well-being, intimacy, social interaction, communication and opportunities to resolve issues from the past. -personal growth from trauma includes becoming more caring and connected to others, identifying personally meaningful aspects of life, and reassigning priorities. -Adult children used more substances, venting, reframing and humour to cope than spouses of ppl with AD used.	(none)	Brief Cope Inventory	CES-D	Dementia
93.	Papastavrou, E., Charalambous, A., Tsangari, H., & Karayiannis, G. (2012). The burdensome and depressive experience of caring: What cancer, schizophrenia, and Alzheimer's disease caregivers have in common. *Cancer Nursing, 35*(3), 187–194.	- study in Cyprus with Greek Zarit burden interview and Greek CESD with caregivers of people with cancer, Alzheimer's disease, or schizophrenia. - highest burden in AD caregivers, highest depression in Cancer caregivers. Lowest depression in AD caregivers but still reached significant level.	Zarit	(none)	CES-D	Dementia
94.	Papastavrou, E., Kalokerinou, A., Papacostas, S. S., Tsangari, H, & Sourtzi, P. (2007). Caring for a relative with dementia: Family caregiver	Outcome: 68% of dementia caregivers endorsed high burden and 65% of dementia caregivers exhibited sx of depression. Women scores were higher for burden and higher for feeling social deprivation - high burden significantly associated with use of	Zarit	Ways of Coping Questionnaire	CES-D	Dementia

	burden. *Journal of Advanced Nursing, 58*(5), 446–457.	emotionally-focused coping strategy, i.e., wishful thinking - below average burden significantly associated with problem solving and seeking social support - female caregivers more likely to use seeking social support and wishful thinking than male caregivers.				
95.	Petkus, A. J., Gum, A. M., Small, B., Malcarne, V. L., Stein, M. B., & Loebach Wetherell, J. (2010). Evaluation of the factor structure and psychometric properties of the Brief Symptom Inventory-18 with homebound older adults. *International Journal of Geriatric Psychiatry, 25*, 578–587.	Used BSI-18 subscales derived directly from BSI-53. Cited Derogatis BSI-18 manual as identifying t-score of 63 to indicate significant distress based on community norms. Sample of homebound older adults with a mean age of 74.7 years old Males *n* = 29; Females *n* = 113 Depression subscale sum of the means of 6 items = 4.15 (standard deviation 5.24) This subscale score was translated into a t-score of 51.61.	(none)	(none)	BSI	Older Adults
96.	Pinquart, M., & Sörensen, S. (2006). Helping caregivers of persons with dementia: Which interventions work and how large are their effects? *International Psychogeriatrics, 18*(4), 577–595.	Metaanalysis. Outcome: small effect sizes for interventions impact on burden, depression of caregivers for ppl w dementia. Most successful were multicomponent interventions targeted to specific needs of individual caregivers.	(none)	(none)	(none)	Recommendations
97.	Plassman, B. L., Langa, K. M., Fisher, G. G., Heeringa, S. G., Weir, D. R., Ofstedal, M. B., . . . Wallace, R. B. (2007). Prevalence of Dementia in the United States: The aging,	Researchers conducted Aging, Demo-graphics, and Memory Study (ADAMS) for all regions of USA. Sample included 1770 people over 71 years old. The Population was a Health and Retirement study that included 22,000 people between July 2001 and Dec 2003 at Duke Univ and UMichigan. Collected	(none)	(none)	(none)	Demographics

	Demo-graphics, and memory study. *Neuroepidemiology, 29*, 1–132.	hx, neuropsych testis, APOE DNA, neurological exam. Final *n* = 856 Outcome: 13.93% of population report dementia; significant predictors = older age, fewer years education, 1+ APOE E4 allele. Gender and race not predictive of dementia. - over age 90 dementia prevalence is 37.4% of sample.				
98.	Raccichini, A., Castellani, S., Civerchia, P., Fioravanti, P., & Scarpino, O. (2009). The caregiver's burden of Alzheimer patients: Differences between live-in and non-live-in. *American Journal of Alzheimer's Disease & Other Dementias, 24*(5), 377–383.	Outcome: CBI higher for live-in than non-live-in. Spouses feel less objective burden than children who live with care recipient, possibly because they feel naturally responsible for spouse than children feel naturally responsible for their parents so it's easier to bear.	CBI	(none)	(none)	Dementia
99.	Radloff, L. S. (1977). The CES-D: A self-report depression scale for research in the general population. *Applied Psychological Measures, 1*(3), 385–401.	CES-D Sample Q1 *n* = 2514, mean = 9.25 *SD* = 8.58 Sample Q2 *n* = 1060 mean = 8.17, *SD* = 8.23 Sample Q3 *n* = 1422, mean = 7.94, *SD* = 7.53 Psych sample *n* = 70, mean = 24.42, *SD* = 13.51	(none)	(none)	(none)	(none)
100.	Razani, J., Corona, R., Quilici, J., Matevosyan, A. A., Funes, C., Larco, A., . . . Lu, P. (2014). The effects of declining functional abilities in dementia patients and increases in psychological distress on caregiver burden over a one-year	Outcome: caregiver overall burden is higher in caregivers with baseline anxiety and depression, and caregiver burden level increases more after a year in anxious and depressed caregivers than it does in caregivers with subclinical psych distress at baseline. Important to provide caregiver support to prevent exponential increases in burden and declines in mental health. Depre at baseline predicts caregiver perceptions of	CBI	(none)	BSI	Dementia

	period. *Clinical Gerontologist, 37*, 235–252.	time restrictions, out of sync with peers, fatigue and poor physical health. Anx at baseline predicts caregiver perceptions of physical burden Feelings of hostility and anger towards their situation results in greater feelings of social isolation and conflict.				
101.	Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, Pl, Marvardi, M. Polidori, M. C., . . . Study Group on Brain Aging of the Italian Society of Gerontology and Geriatrics (2005). Predictors of high level of burden and distress in caregivers of demented patients: Results of an Italian multicenter study. *International Journal of Geriatric Psychiatry, 20*, 168–174.	Outcome: highest levels of burden, distress, depression & anxiety in caregiver are correlated with female, co-residing with care recipient, 70 years + old, and if recipient is spouse. - highest level of distress is related to patient apathy - patient characteristics that predict high caregiver burden and distress are: agitation, irritability, motor aberrations, aberrant nighttime behaviours… possible because they require continuous monitoring	CBI	(none)	BSI	Dementia
102.	Russo, J., Vitaliano, P. P., Brewer, D. D., Katon, W., & Becker, J. (1995). Psychiatric disorders in souse caregivers of care recipients with Alzheimer’s disease and matched controls: A diathesis-stress model of psychopathology. *Journal of Abnormal Psychology, 104*(1), 197–204.	Longitudinal study over 18 mos. Psych hx of lifetime prevalence prior to care receiver getting Alzheimer’s disease. 42% of caregivers had previous dx vs. 37% of noncaregivers had previous dx. Significantly more caregivers than noncaregivers had a depression or anxiety dx after onset of AD sx. (29% vs 12%) Significantly more caregivers had an MDD episode than noncaregivers (20% vs. 7%)	(none)	(none)	(none)	Dementia

103.	Rymer, S., Salloway, S. Norton, L., Malloy, P., Correia, S., & Monast, D. (2002). Impaired awareness, behavior disturbance, and caregiver burden in Alzheimer Disease. *Alzheimer Disease and Associated Disorders, 16*(4), 248–253.	Outcome – behavioural disturbance makes a significant contribution to caregiver burden however patient's awareness of own memory deficit does not appear to contribute to burden	Zarit	(none)	(none)	Dementia
104.	Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies, 32*, 495–523.	Used Marwit and Meuser Caregiver Grief Inventory Short Form. -Grief defined as "reaction to the perception of loss" incl. sx of sadness, regret, guilt, emotional pain, anxiety, loneliness, anger. Marwit and Meuser (2005) stated that family members of ppl w dementia experience grief closer to post death grief than loved ones of other terminal illnesses, who experience anticipatory grief because cognitive decline precludes pt's ability to participate in closure. Attachment bonds deteriorate prior to death and "create a sense of ambiguity in the relationship… in that the care recipient is physically present but psychologically absent." Depression focus on negative interpretation of self and world vs grief focus on separation distress *considerable portion of depression sx in caregivers for dementia ppl can be accounted for by grief. Outcome: Spouses grief more yearning for past, feeling isolated and stressed. Adult children grief more guilt and regret and frustration with systemic barriers to parents' care. Recommendations: help build a support network	(none)	(none)	(none)	Recommendations

		(support groups, educational programs, counseling, family meetings, pets, spiritual group)				
105.	Schneider, J., Murray, J., Banerjee, S., & Mann, A. (1999). Eurocare: A cross-national study of co-resident spouse carers for people with Alzheimer's disease: I - Factors associated with carer burden. *International Journal of Geriatric Psychiatry, 14*, 651–661.	Study based on Pearlin et all stress process model indicating bidirectional causation of primary stressors (caring tasks), secondary stressors (role & relationship conflicts; intrapsychic strains such as motivation for caring and impact of caring on carer's self-image); all forms of stress moderated by social support and coping strategies. -Outcome: Carer burden strongly related to psychological distress across 14 EU countries.	Zarit	(none)	GHQ-12	Dementia
106.	Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas, 66*, 191–200.	Metaanalysis of depression in caregivers of ppl w dementia who live at home. Outcome: 1/3 caregivers experience depression. More common in dementia caregivers than in caregivers for other chronic illnesses. Depression impacted by continuous grief and uncontrollable nature of illness. Tables include cut-off for significance. Included studies dated 1990 – 2009 Independent studies in their metaanalysis showed a range of 30% to 80% of depression rates in caregivers depending on the population and recruiting method used	(none)	(none)	(none)	Dementia
107.	Schulz, R. & Martire, L. M. (2004). Family caregiving of persons with dementia. *American Journal of Geriatric*	Overview of stressors of caregiving in dementia, impact on caregiver health, areas for interventions to support caregivers, AMA recommendations for physicians treating ppl w dementia on how to support caregivers (medical referral, support group referral,	(none)	(none)	(none)	Recom-mendations

	Psychiatry, 12(3), 240–249.	respite referral). Am Assoc for Geriatric Psychiatry recommends that counseling for caregiver be reimbursable service because of caregiver's role in monitoring and managing pt so it's important to receive guidance from physician. Overview of ideas for future interventions to support caregivers.				
108.	Selwood, A., Johnston, K., Katona, C., Lyketsos, C., & Livingston, G. (2007). Systematic review of the effect of psychological interventions on family caregivers of people with dementia. *Journal of Affective Disorders, 101*, 75–89.	Cites Sorensen et al 2002 that group interventions less efficacious than individual interventions for caregivers of ppl w dementia. Metaanalysis of 62 studies of psychological interventions for dementia caregivers. Outcome: multiple studies showed 6+ sessions of individual behavioural management techniques had excellent immediate and 4-12 months follow up reduction in depression sx reported in caregiver. Interventions included: role play, education about specific behaviours , stress mgmt, improving pleasant events for the pt, caregiver support group. However, many other studies also showed no difference btwn intervention and control groups. Education alone is inefficacious – needs to be individually tailored to link educ to practicalities of caregiver's presenting stressors Supportive thpy alone also not efficacious	(none)	(none)	(none)	Recommendations
109.	Seng, B. K., Luo, N., Ng, W. L., Lim, J., Chionh, H. L., Goh, J., & Yap, P. (2010). Validity and reliability of the Zarit Burden Interview in	Singapore study of English-literate carers to found Zarit Burden Interview to be relevant to an Asian population	Zarit	(none)	(none)	Dementia

	assessing caregiving burden. *Annals of the Academy of Medicine Singapore, 39*, 758–763.					
110.	Sepulveda, A. R., Todd, G., Whitaker, W., Grover, M., Stahl, D., & Treasure, J. (2010). Expressed emotion in relatives of patients with eating disorders following skills training program. *International Journal of Eating Disorders, 43*(7), 603–610.	Follow up on template article after interventions. Interventions to lower EE: psychoeducational skills training program included group workshops with written manual and ppt slides directed at pt's parents. 24% fewer parents were rated high EE following intervention	(none)	(none)	(none)	Recom-mendations
111.	Simonelli, C., Tripodi, F., Rossi, R., F., Fabrizi, A., Lembo, D., & Pierleoni, L. (2008). The influence of caregiver burden on sexual intimacy and marital satisfaction in couples with an Alzheimer spouse. *International Journal of Clinical Practice, 62*(1), 47–52.	"The main mission of caregiving is to promote independence by maintaining the person's most functional state" Bridges 1995. Outcomes: As AD sx impact marital relationships, there is a correlation between increased burden endorsement and reduced levels of satisfaction with the amount of affection in the relationship. Also correlation between increased burden endorsed and lower levels of sexual marital satisfaction.	CBI	(none)	(none)	Dementia
112.	Sinforiani, E., Pasotti, C., Chiapella, L., Malinveri, P., & Zucchella, C. (2010). Differences between physician and caregiver evaluations in Alzheimer's disease. *Functional*	Outcome – caregivers report significantly more symptoms than physicians evaluate on clinical instruments in terms of ADLs, IADLs, and Neuropsychiatric Inventory (NPI) - no difference detected btwn caregiver and clinical instruments in terms of MMSE. - Caregivers who report less satisfaction with	CBI	(none)	(none)	Dementia

	Neurology, 25(4), 205–209.	pharmacological tx of patient report higher burden and psych distress				
113.	Tan, L., Yap, P., Ng, W. Y., & Luo, N. (2013) Exploring the use of the Dementia Management Strategies Scale in caregivers of persons with dementia in Singapore. *Aging and Mental Health, 17*(8), 935–941.	Original 28 item DMSS was normed in English in USA (Hinrichsen & Niederehe 1995) Singapore study of English-literate carers to amend the DMSS found it to be relevant to an Asian population.	(none)	(none)	(none)	Dementia
114.	Tarrier, N., Barrowclough, C., Ward, J., Donaldson, C., Burns, A., & Gregg, L. (2002). Expressed emotion and attributions in the carers of patients with Alzheimer's disease: The effect on carer burden. *Journal of Abnormal Psychology, 222*(2), 340–349.	Outcome: no difference found between high and low EE carers in terms of patient severity reported on CDR, MMSE, and ADLs - patients with high EE carers reported significantly higher behavioural disturbance, psychotic sx and depression than patient with low EE carers - high EE carers attributed negative events more often to personal and controllable factors of the care recipient than low EE carers. - High criticism and hostility by the carer was related to internal, personal & controllable patient attributions made about the recipient Summary: beliefs that patients behaviour is less volitional resulted in carers expressing more warmth and enjoyment of the patient's company and more appreciation for themselves in their roles as caregivers.	(none)	Camberwell CFI	GHQ-28	Dementia
115.	Tremont, G., Davis, J., Papandonatos, G. D., Grover, C., Ott, B. R., Fortinsky, R. H., Gozalo, P., & Bishop, D. S. (2013). A telephone intervention for dementia caregivers:	Designed therapist delivered telephone support protocol to address caregiver burden and distress but not case mgmt. Trial not yet completed.	Zarit	(none)	CES-D	Dementia

	Background, design, and baseline characteristics. *Contemporary Clinical Trials, 36*(2), 338–347.					
116.	United States Congress Senate Special Committee on Aging. (2012). *Alzheimer's disease and dementia: A comparison of international approaches: Report of the Special Committee on Aging, United States Senate pursuant to S. Res. 81, sec. 17(d), March 2, 2011, resolution authorizing a study of the problems of aged and aging.* Retrieved from http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0CB8QFjAA&url=http%3A%2F%2Fwww.gpo.gov%2Ffdsys%2Fpkg%2FCRPT-112srpt254%2Fpdf%2FCRPT-112srpt254.pdf&ei=jLQZVcGcEY2uogTp74KIBA&usg=AFQjCNEvxTLCTewXQ3Ftd7YVQBRmFPevNA&bvm=bv.89381419,d.cGU	- Dementia global prevalence estimate by WHO 2011 = 35.6 million. 2-10% cases in ppl under 65 yrs old. 25-30% of ppl 85+ yrs old. - Definition dementia by WHO: “a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in a large number of conditions primarily or secondarily affecting the brain.” - Risks of dementia #1 = older age. AD risk includes heavy alcohol use, head injury, tbi. VD risk includes heart disease, stroke, diabetes. - Protective factors = higher educ, cognitive activity, higher SES, certain genetic mutations. - financial cost to caregivers = foregone or curtailed employment, worsening health related to own stress (incl stress from stigma)	(none)	(none)	(none)	Demo-graphics
117.	United States General Accounting Office. Report to the Secretary of Health and Human Services.	Estimated AD in US popln of any severity in 1995 5.7 % Moderate to severe 3.3% Projected estimates of total AD: 1995 1,906,822	(none)	(none)	(none)	Demo-graphics

	(1998). Alzheimer's disease: Estimates of prevalence in the United States. Retrieved from http://www.gao.gov	2000 2,141,772 (12%incr) 2015 2,872,420 (51% incr)				
118.	Upton, N., & Reed, V. (2006). The influence of social support on caregiver coping. *International Journal of Psychiatric Nursing Research, 11*(2), 1256–1267.	Phenomenological study of 46 caregivers of ppl with dementia in England. To describe the first hand phenomenon of caregiver coping in dementia. 1) All caregivers reported psychophysical distancing of family and friends – they did not offer or give direct physical care to the pt or to ease the caregiver's physical exhaustion. Rarely directly ask how caregiver is coping. 2) Some caregivers did not get regular social contact. In those who continued in regular family/friend relationships, others tend to sideline the pt as if invisible during the social activity. Relatives focus on socializing with the carer without providing backup sitting service for the pt. Commonly caregiver explains that relatives don't visit because it upset them to see the changes in the pt. 3) Caregiver tried to protect their children by deliberately keeping them "in the dark" about how much burden the caregiving causes. Caregiver feels moderately to severely uncomfortable in social situations because of the dementia pt's difficulty sustaining rational conversation. Caregiver feels both socially betrayed/disappointed by friends/relatives and simultaneously relieved when socializing is reduced. 4) Telephone socializing very helpful for feeling safety network and less isolation, and takes of stress	(none)	(none)	(none)	Recommendations

		of getting ready and going out and possibly arranging sitting service. 5) All participants regarded caregiving of spouse as their sole responsibility and they did not want to pass it off to another person. But they would appreciate visitors for the pt and occasional sitting service at home if a relative/friend would take responsibility for spending personal time with the pt.				
119.	Uwakwe, R., Ibeh, C. C., Modebe, A. I., Bo, E., Ezeama, N., Njelita, I., Ferri, C. P., & Prince, M. J. (2009). The epidemiology of dependence in older people in Nigeria: Prevalence, determinants, informal care, and health service utilization. A 10,66 dementia research group cross-sectional survey. *Journal of the American Geriatrics Society, 57,* 1620–1627.	Nigeria largest African nation and 3% of population age 65+. Life expectancy 46 y.o male/47 y.o. female. Migration from rural areas means less kinship support systems for older adults. Dementia determined by Community Screening Instrument for Dementia memory items, 10 word list immediate and delayed recall (dx dementia for 1.5 sd below age and education norms) *n* = 872 79.2% memory not impaired 11.3% impairment on 1/3 memory tests 4.9% impairment on 2/3 memory tests 4.6% impairment on 3/3 memory tests 25.6% clinically elevated depression sx Caregivers: 68% were the child or child-in-law 13.7% was the spouse ZBI for overall group was 7.8 sd 6.3 ZBI for memory impaired group was 9.8 sd 8.1	Zarit	(none)	Geriatric Mental State structured interview	Dementia
120.	Uwakwe, R. & Modebe, I. (2007). Disability and caregiving in old age in a Nigerian community.	Most care for elderly in Nigeria is by family members (58% spouse, 42% children, grandchildren, great grandchildren, children in law)	Zarit	(none)	GHQ-12	Elderly

	Nigerian Journal of Clinical Practice, 10(1), 58–65.	Catholic church provides limited institutional care for destitute elderly who have no living or local family. No government or other community agencies provide help for care of disabled elderly. Authors call for joint responsibility of agencies to assist families. GHQ-12 results not reported Zarit 22-item interview was collapsed into a general interview. 97.5% of caregivers indicated that “providing care for their older relatives was a very heavy burden to them” with impact on work, school, including missing work days or cutting back hours. n = 90 caregivers (84 female, 6 male)				
121.	Van Humbeeck, G., Van Audenhove, C. De Hert, M., Pieters, G., & Storms, G. (2002). Expressed emotion: A review of assessment instruments. *Clinical Psychology Review, 22*(3), 321–341.	Use of Expressed Emotion measures (CFI plus 11 others) reliably predicts relapse rate in psychiatric pts and evaluates emotional climate between caregiver and patient. CFI is found to be the best assessment instrument. Other instruments have significant correlations btwn relapse and EE but not found to be as powerful as CFI.	(none)	CFI FMSS PPI LEE IRQ PCS FEICS PRS QAEE AC FAS FES	(none)	Psychiatric patients
122.	Vaughn, C. E. (1989). Annotation: Expressed emotion in family relationships. *Child Psychology and Psychiatry, 30*(1), 13–22.	Recaps 3 other studies and says it’s 3 – 4 times more likely for schizophrenia patients to relapse within 9 months of hospital discharge if patient returns to home rated high EE upon interview at initial admission. Relatives’ EE at admission is significantly highest predictor of symptom relapse over all clinical features. - Similarity between schizophrenia and dementia could be both are vulnerable cognitively so it is “difficult to process complex stimuli and deal with social relationships”	(none)	(none)	(none)	Schizophrenia

		Therefore high EE is overarousing.				
123.	Vaughn, C. & Leff, J. (1976). The measurement of expressed emotion in the families of psychiatric patients. *British Journal of Social and Clinical Psychology, 15*, 157–165.	Original Camberwell interview by Brown 1966 took 4-5 hours and covered all aspects of family life. When significance was found for emotion scales, Brown & Rutter shortened the interview to 1-2 hours and focused on 3 topics that were found to be the topics in which 67% of critical remarks were made: psychiatric history, irritability & quarrelling, and clinical sx in past 3 months prior to hospital admission. Outcome: the majority of critical comments occurred in 1st 60 minutes - 1st 60 minutes of interview had same predictive validity as longer interview for EE & readmission.	(none)	Camberwel l	(none)	Schizo-phrenia
124.	Vitaliano, P. P., Becker, J., Russo, J., Magana-Amato, A., & Maiuro, R. D. (1988-89). Expressed emotion in spouse caregivers of patients with Alzheimer's disease. *Journal of Applied Social Sciences, 13*, 215–250.	Seminal study of EE applied to dementia caregivers. Focus on spouses of people with Alzheimer's disease. Outcome: high EE related to more depression, more burden, more anger held-in and less anger control than low EE caregivers. - high EE used more avoidance in coping - high EE used less coping by counting one's blessings - high EE perceived more functional impairment in their spouses than low EE caregivers	(none)	FMSS	BDI	Dementia
125.	Vitaliano, P. P., Young, H. M., Russo, J., Romano, J., & Magana-Amato, A. (1993). Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer's disease? *Journal of Gerontology,*	Outcome: disruptive behaviours by care recipient are more frequent and are susceptible to the influence of caregiver EE-critical. Cognitive and ADL decline in functioning are not predicted by EE-critical. Disruptive behaviours are defined as paranoia (hiding things), anger, abusiveness toward caregiver.	(none)	FMSS (use baseline data)	BDI (use baseline data)	Dementia

	48(4), P202–P209.					
126.	Vitaliano, P. P., Zhang, J., & Scanlan, J. M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin, 129*(6), 946–972.	-chronic stressors of caregiving includes "prolonged anticipatory bereavement over lost aspects of their relationships with their care recipients" Metaanalysis compared 1594 caregivers of ppl w dementia with 1478 demographically similar noncaregivers. Outcome: 9% greater risk of health problems in caregiver group; 23% higher level of stress hormones than noncaregivers, which is related to elevated blood pressure and glucose levels and in turn related to hypertension and diabetes; 15% poorer antibody production in caregivers which is related to greater risk for flu and pneumonia.	(none)	(none)	(none)	Demo-graphics
127.	Wagner, A. W., Logsdon, R. G., Pearson, J. L., & Teri, L. (1997). Caregiver expressed emotion and depression in Alzheimer's disease. *Aging & Mental Health, 1*(2), 132–139.	Outcome: 40% of caregivers were classified as high EE and 60% low EE. High EE = -ve initial stmt, -ve relationship rating, or 1+ criticisms; or if excessive overprotective behaviour and/or respondent cried during interview. Low EE if not high EE. - High EE caregivers more likely to receive depression dx compared to low EE caregivers - High EE caregivers reported higher Zarit Burden scores and lower positive burden scores than low EE caregivers	Zarit	FMSS	CES-D	Dementia
128.	Weardon, A. J., Tarrier, N., Barrowclough, C., Zastowny, T. R., & Rahill, A. A. (2000). A review of expressed emotion research in health care. *Clinical Psychology*	High EE ratings by close relatives has shown to be predictive of sx relapse or severity in studies of patients diagnosed with schizophrenia, depression , bipolar d/o, cystic fibrosis, eating disorders, PTSD, alcohol abuse, personality d/o, agoraphobia, child/adolescent behavioural issues, AD, dementia, diabetes, asthma,	(none)	(none)	(none)	Dementia Arthritis Asthma Diabetes Epilepsy Heart Surgery Obesity

	*Review, 20(*5), 633–666.	epilepsy, arthritis, heart surgery, and obesity.				
129.	World Health Organization & Alzheimer's Disease International. (2012). *Dementia: A public health priority.* Retrieved from http://www.who.int/mental_health/publications/dementia_report_2012/en/	Worldwide, an estimated 35.6 million people are currently living with dementia This number is projected to reach 115.4 million people by 2050	(none)	(none)	(none)	Dementia
130.	Wu, H., Wang, J., Cacioppo, J. T., Glaser, R., Kiecolt-Glaser, J. K., & Malarkey, W. B. (1999). Chronic stress associated with spousal caregiving of patients with Alzheimer's dementia is associated with downregulation of B-lymphocyte GH mRNA. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences, 54*(4), M212-215.	Outcome: compared with matched noncaregivers, caregivers of patients with AD had significantly reduced immune function while actively caregiving and for several years after their care recipient has died. Including decreased response by B-cells – propose that this is due to social isolation and chronic stress associated with providing care for patients with AD.	(none)	(none)	(none)	Dementia
131.	Yap, P., Luo, N., Ng, W. Y., Chionh, H. L., & Goh, J. (2010). Gain in Alzheimer care instrument: A new scale to measure caregiving gains in dementia. American Journal of Geriatric Psychiatry, 18(1), 68–76.	Singapore study of English-literate carers to amend the DMSS so it will be more relevant to an Asian population.	Zarit	(none)	DMSS	Dementia
132.	Zabala, M. J., Macdonald, P., & Treasure, J.	Used as template for study design.	(none)	(none)	(none)	Eating Disorders

	(2009). Appraisal of caregiving burden, expressed emotion and psychological distress in families of people with eating disorders: A systematic review. *European Eating Disorders Review, 17*, 338–349.	Metaanalysis included 20 studies measuring caregiver burden, psych distress, and expressed emotion in caregivers of people with eating disorders. ED caregivers have higher EE than controls in studies that used controls. ED caregivers have comparable levels of burden as caregivers of people with depression and in some cases as high or higher burden as caregivers of people with psychosis.				
133.	Zanetti, O., Geroldi, C., Frisoni, G. B., Bianchetti, A., & Trabucchi, M. (1999). Contrasting results between caregiver's report and direct assessment of activities of daily living in patients affected by mild and very mild dementia: The contribution of the caregiver's personal characteristics. *Journal of the American Geriatrics Society, 47*(2), 196–202.	Outcome – Caregiver's who score high on Time Dependence burden (feel restricted from other activities due to caregiving responsibilities) tend to report poorer performance-based abilities in patients than their physicians observe. - caregivers with greater # of depressive sx tend to rate the pt with slower/poorer motor abilities than their physicians observes	CBI	(none)	BDI	Dementia
134.	Zarit, S. H. (2008). Diagnosis and management of caregiver burden in dementia. In C. Duyckaerts & I. Litvan (Eds.). Handbook of Clinical Neurology, Vol. 89 (3rd series): Dementias. Oxford: Elsevier.	Reason to assess burden is because managing caregiver's burden reduces risk of adverse effects on caregiver's physical and psychological well-being and thereby allows pt to receive care for a longer time. Looking at caregiving stress from multiple dimensions helps clinician understanding primary objective demands and subjective meaning of these stressors on individual caregivers. Also	(none)	(none)	(none)	Recom-mendations

		looks at secondary stressors, which are things that interfere with caregiver's roles outside the immediate relationship with pt, such as work and extended family impacts. Being active caretaker via planning and learning new strategies for responding to memory loss and being optimistic result in less caregiver burden. Emotional support and physical relief from paid or friend/family also reduces burden. Clinician should look for signs pt neglect that may be due to caregiver's lack of understanding of pt's condition; caregiver inadequate sleep, eat too much or too little, alcohol/drug use for coping, fail to seek med attn for own health; husband caregiver may not be skilled at preparing balanced meals so impacts health; risk of depression and suicide in caregiver; rarely but some cases homicide by caregiver; caregiver need for respite and provide resource referral. Caregiver support book The 36 Hour Day by Mace and Rabins 2006. Caregiver support groups and Alzheimer's Assoc groups that help caregiver understand why pts engage in dementia related behs and increase sympathetic stance, legal issues like power of attny. Behavioural management strategies can reduce depressive behaviours in the pt like regular bedtime, regular waking time, quiet routine, time outdoors in daylight, reduce caffeine and stimulants and naps – all these things improve				

		pt's sleep and thereby improve caregiver's sleep. Family support meeting regularly helps reduce burden, caregiver feels understood and reduces family conflict Area Agencies on Aging provide referrals for financial assistance for paid help.				
135.	Zarit, S. H., Anthony, C. R., & Boutselis, M. (1987). Interventions with care givers of dementia patients: Comparison of two approaches. *Psychology and Aging, 2*(3), 225–232.	Time-limited (8 sessions) intervention focused on teaching behavioural problem solving, providing psychoeducation abt dementia, and identifying informal and formal sources of caregiver support. Delivered via: a) support groups b) individual/family counselling Outcome: Both interventions produced lower reports of burden and distress but not signif diff from control groups (ppl on waiting list). Possibly the decision to seek help, the initial intake interview, and expectation of receiving help may have produced change in wait list group.	(none)	(none)	(none)	Recommendations
136.	Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist, 20*(6), 649–655.	Article contains the actual questionnaire. Outcome: there is a strong relationship between lower caregiver burden and frequency of visits from family members suggesting that resources from the caregiver/patient's natural support system serve to reduce the caregiver's burden/distress.	Zarit	(none)	(none)	General Population
137.	Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression scale. *Acta Psychiatrica Scandinavica, 67*(6), 361–370.	HADS 0-7 normal 8-10 borderline 11-21 abnormal	(none)	(none)	(none)	(none)
138.	Zucchella, C., Bartolo, M., Pasotti, C., Chiapella, L., &	Outcome – in early stages of AD, caregivers feel the most burden due to time	CBI	COPE	(none)	Dementia

	Sinforiani, E. (2012). Caregiver burden and coping in early-stage Alzheimer disease. *Alzheimer Disease and Associated Disorders, 26*(1), 55–60.	needed to supervise the patient on ADLs - the second highest burden was feeling developmental burden, i.e. that they were missing opportunities in life that their same-age peers were able to take part in. - The use of avoidance strategies significantly predicts high levels of caregiver distress. No other coping factor is significantly related to burden.				

APPENDIX B
IRB Exemption Letter

PEPPERDINE UNIVERSITY
Graduate & Professional Schools Institutional Review Board

November 10, 2015

Susan Sprokay

Project Title: Appraisal of Caregiving Burden, Expressed Emotion, and Psychological Distress in Families of People with Dementia: A Systematic Review
Re: Research Study Not Subject to IRB Review

Dear Ms. Sprokay:

Thank you for submitting your application, *Appraisal of Caregiving Burden, Expressed Emotion, and Psychological Distress in Families of People with Dementia: A Systematic Review*, to Pepperdine University's Graduate and Professional Schools Institutional Review Board (GPS IRB). After thorough review of your documents you have submitted, the GPS IRB has determined that your research is **not** subject to review because as you stated in your application your dissertation ***research*** study is a "critical review of the literature" and does not involve interaction with human subjects. If your dissertation research study is modified and thus involves interactions with human subjects it is at that time you will be required to submit an IRB application.

Should you have additional questions, please contact the Kevin Collins Manager of Institutional Review Board (IRB) at 310-568-2305 or via email at kevin.collins@pepperdine.edu or Dr. Judy Ho, Faculty Chair of GPS IRB at gpsirb@pepperdine.edu. On behalf of the GPS IRB, I wish you continued success in this scholarly pursuit.

Sincerely,

Judy Ho

Judy Ho, Ph. D., ABPP, CFMHE
Chair, Graduate and Professional Schools IRB

cc: Dr. Lee Kats, Vice Provost for Research and Strategic Initiatives
Mr. Brett Leach, Compliance Attorney
Dr. Shelly Harrell, Faculty Advisor