

Improving Provider Awareness of Caregiver Burden in an

Oregon Alzheimer's Disease & Dementia Care Center

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Abstract

Purpose: The purpose of this project was to design a plan for assessing caregiver burden in an Oregon Alzheimer's & Dementia Care Center (ADCC). The tool chosen was a shortened form of the Zarit Burden Interview (ZBI).

Design & Methods: A short-form ZBI score cutoff was established based upon research suggesting a correlation between ZBI scores and symptomatic depression. To validate this score demographic information of caregivers being seen at the OR ADCC was compared to two studies examining ZBI scores and caregiver demographics across large sample populations. To accomplish this, caregivers arriving with patient at the ADCC were given surveys including the short-form ZBI and demographic questions over a 3-month period.

Results: Forty-six surveys were used for final statistical analysis. Mean short-form ZBI score was 7.24/16 (sd=4.05). The average age of participants was 61.54 years old, ranging from 31-89. The majority was female (28, 60.87%), married (40, 86.96%), unemployed (25, 54.34%), and spouses (28.26%) or daughters (15.22%).

Implications: A short-form ZBI score of five was established as an appropriate cutoff for identifying elevated risk of symptomatic depression in caregivers. Good correlation was demonstrated between the two comparison studies and this sample population. The ZBI was found to be a suitable tool for the assessment of caregiver burden. Further study should be conducted before implementation of this caregiver burden assessment strategy in other institutions. Additionally, study should be directed toward establishing further clinically relevant outcomes of elevated ZBI scores.

Since the 1980's, there has been an increased interest in the experience of caregivers and the consequences of caregiving. Researchers Pearlin, Mullan, Semple, and Skaff (1990) wrote about the "flourishing enterprise" of caregiving research, and cited the shifting demographic of an aging population as the reason for this growing interest. Much of the research has been directed toward the *burden* generated by caregiving and multiple assessment tools have been developed to measure different aspects of this issue (Family Caregiver Alliance, 2012).

Burden has been described as the caregiver's perception of subjective factors such as feelings of stress or strain (Bédard, Pedlar, Martin, Malott, & Stones, 2000). Pearlin et al. (1990) defines these stressors as either primary or secondary. *Primary* refers to those stressors directly related to the needs of the patient and the restructuring of the caregiver/care recipient relationship (e.g. care recipient behavioral problems, caregiver relational deprivation). *Secondary* stressors encompass problems and hardships caused by primary stressors (e.g. family conflict, perceived lack of competence). These multifactorial stressors and the cumulative *burden* on both the caregiver and care recipient are far reaching and have significant implications.

In their 1967 study, *Aging and Mental Disorder in San Francisco*, Lowenthal & Berkman described the psychological, physical, and financial cost to families providing at-home caregiving. As investigation of caregiver *burden* (CB) has continued, *burden* effects have been more specifically defined. The negative consequences of CB include increased incidence of caregiver depression, coronary heart disease, physical disabilities that limit activity, and chronic health conditions such as asthma and diabetes (Lee, Colditz, Berkman, & Kawachi, 2003; Strawbridge, Wallhagen, Shema, & Kaplan, 1997). Measures of CB have also been correlated with increased caregiver anxiety and feelings of social isolation, higher use of psychoactive

medications, poorer caregiver perceived physical health, compromised immune function, and an increased risk of all-cause mortality (Kiecolt-Glaser & Glaser, 2001; Sherwood, Given, Given, & von Eye, 2005; Legg, Weir, Langhorne, Smith, & Stott, 2013; Lovell & Wetherell, 2011).

The negative effects of CB are not just limited to the caregiver. Increased levels of *burden* are associated with a higher incidence of elder abuse and can contribute to the decision to institutionalize an elderly family member (Johannesen & LoGiudice, 2012; Bédard et al., 2000). This decision to institutionalize often does not relieve the stress associated with caregiving (Lieberman & Lawrence, 2001), and nursing home placement is expensive for both public and private payers (Rhoades & Sommers, 2003). Not only has institutionalization been shown to increase cognitive decline in nursing home patients (Harmand et al., 2014), but it has also been linked with increased rates of depression and mortality (Miu & Chan, 2011; Wolinsky, Callahan, Fitzgerald, & Johnson, 1992).

Dementia and Caregiving in Oregon & The United States

In 2006, 13.9% of individuals over the age of 71 in the United States (US) were diagnosed with Alzheimer's disease and related dementias (ADRD) (Plassman et al., 2007). This percentage is expected to increase to 20% by the year 2030 (Institute of Medicine [IOM], 2008). A more recent estimate of the prevalence of dementia found that 5.2 million Americans carry the diagnosis of Alzheimer's disease, the most prevalent form of dementia (Herbert, Weuve, Scherr, & Evans, 2013). In Oregon, up to 70% of those with ADRD live in community settings (State Plan for Alzheimer's Disease in Oregon, 2012) and much of this growing population requires support from an informal care source. This is often a spouse, child, or other family member (Fisher et al., 2011). Persons with dementia are more likely to require informal support due to the often-progressive nature of this condition and its ability to impair the cognitive and functional

abilities of the affected individual. Family members, friends, or relatives may take up the task of caregiving and are labeled as informal caregivers due to their lack of substantive training. These caregivers are primarily women (65%), married or in a long-term relationship (71%), younger than 65 (79%), college educated (44%), and currently employed, a student or a homemaker (64%) (Bouldin & Andresen, 2010).

Informal caregiving has been defined as, “activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves” (Pearlin et al., 1990). This care is unpaid and can transfer significant financial burden to the caregiver. In fact, a 2010 MetLife survey, found that the average working caregiver lost more than \$659,000 dollars in their lifetime due to their caregiving responsibilities (MetLife, 2010). The economic impact of informal caregiving is even more startling when considering that there are currently more than 15 million Americans providing unpaid care for individuals with AD/DRD (Alzheimer’s Association, 2014). Of this group, over 173,000 reside in Oregon and they provided greater than \$2.44 billion worth of unpaid care in 2013 (Alzheimer’s Association, 2014). Considering the physical, emotional, social, and economic impact of caregiving and CB on caregivers, care recipients, and the community, it is easy to see why assessment and management of CB will continue to become more important as the population ages.

Assessment of Caregiver Burden in an the Clinical Setting

In 2005, a National Consensus Development Conference of the Family Caregiver Alliance set forth a series of guidelines emphasizing caregiver assessment as a key component of the family centered perspective of healthcare delivery (Family Caregiver Alliance, 2006a). The guidelines recognize the need for longitudinal and periodic assessment of care outcomes for the care-recipient and the family caregiver. Though issues surrounding CB have been recognized for

many years, implementation of a systematic assessment plan within the clinical setting has proved challenging (Collins & Swartz, 2011). Problems affecting the implementation of such interventions may include limited resources supporting specific assessment plans, perceived lack of access to interventions among providers, the perception that the caregiver is not the patient, and the potential for caregiver assessment to cut into limited appointment times (Family Caregiver Alliance, 2006b).

The purpose of this project is to address these issues with the goal of designing a plan for implementation of caregiver *burden* assessment within the setting of an ADCC in Oregon. The Zarit Burden Inventory (ZBI) (Zarit & Reever, 1980) was used to assess CB due to its ease of use and the extent to which it has been clinically studied (Durme, Macq, Jeanmart, & Gobert, 2012). The center participating in this project was using an assessment tool known as the Multidimensional Caregiver Strain Index (MCSI). Due to lack of research to support the use of this tool within the population of individuals caring for people with ADRD, the center expressed interest in transitioning to a short version of the ZBI. Though there are many CB and stressor assessment tools available (Family Caregiver Alliance, 2012), few have been as extensively studied and validated as the ZBI. Literature reviewed in this paper provided support for discontinuing the use of the MCSI and implementing a plan for caregiver assessment using a short form of the ZBI.

The primary goal is to design and implement a method for gathering CB data and presenting the information in a user friendly form within the currently used electronic medical record (EMR) interface. During the course of this project, literature was reviewed to establish clinically relevant cutoffs for *burden*-related intervention and to identify evidence-based CB interventions.

A Literature Review of Burden Assessment

Literature Search Methods

An initial search for name “Zarit” in PubMed with the date range of 1970 to 1990 found the first documents published by Zarit and colleagues referring to the ZBI, initially known as “The Burden Inventory”. Additional search engines used for this review included Ovid MEDLINE, Scopus, & Google Scholar. Key terms Zarit, burden, quality improvement, reliability and validity, Multidimensional Caregiver Strain Index, and the exploded terms elderly, caregiver, and dementia were used with exclusion criteria including English language, and full text availability. Searches were initially restricted to publication within the last ten years but this literature review also presents foundational literature key to this topic stretching as far back as 1978. All together, 15 articles were chosen for this review.

Multidimensional Caregiver Strain Index (MCSI)

The MCSI is a caregiver assessment tool that is currently endorsed by the National Parkinson’s Foundation as the primary tool for assessing *burden* in caregivers of individuals with Parkinson’s disease (Okun, 2013). The tool is an 18-question survey and measures six-dimensions of caregiver strain including physical, social, interpersonal, and financial strain, time constraints, and demanding/manipulative behavior on the part of the elder (Stull, 1996). Items are scored using a Likert scale ranging from 0-4 with a potential score range of 0-72. Few studies have addressed the validity or reliability of this tool. A PubMed search for “Multidimensional Caregiver Strain Index” revealed only four results. In comparison the same search for “Zarit Burden Interview” found 278 results. Beyond the lack of relevant data to support the use of the MCSI, this tool also was not validated in caregivers of individuals with ADRD, currently had no

evidence based interventional cutoff score, and is longer than brief versions of the ZBI. In a paper defining the qualities of a successful questionnaire Gagné & Godin (1999) wrote, “If possible and when psychometric testing is at minimum good, short questionnaires must be preferred.” Due to these reasons, it is understandable that this Oregon ADCC would transition to a version of the ZBI.

ZBI Subscales, Validity, & Reliability

The ZBI was first introduced in 1980 as a 29-question survey used to assess severity of CB (Zarit et al, 1980). The modern version has been reduced to 22-questions with a potential score ranging from 0-88. Each item is answered on a five-point Likert scale: zero for never, one for rarely, two for some-times, three for quite frequently, and four for nearly always. This tool has been shown to have excellent internal consistency ($\alpha=0.83$ and 0.93) (Majerovitz, 1995; Seng et al. 2010), while avoiding the influence of confounders including age, gender, locale, language, living situation, marital status, and employment status (Hébert, Bravo, & Prévile, 2000).

Several studies have identified potential subscales reflected in the ZBI. These include both a five factor subscale, of which one factor was associated with 64 per cent of question-to-question variance, and a three factor subscale that included only 14 of the ZBI's 22 questions (Rankin, Haut, Keefover, & Franzen, 1994; Knight, Fox, & Chou 2000). The most commonly cited subscale includes only two dimensions: role strain and personal strain (Whitlatch, Zarit, & von Eye, 1991). Role strain characterizes stress due to role conflict and overload, while personal strain characterizes how personally stressful the experience of caregiving has become. These dimensions have been validated in further study, though the specific questions associated with each dimension are disputed (Hébert et al., 2000).

While the original tool was based on Zarit and colleague's "clinical experience with caregivers", over time it has shown high validity as an assessment tool. Seng et al. (2010) identified a positive correlation between the ZBI, the Burden Assessment Scale ($r = 0.73$, $P < 0.0001$) and the General Health Questionnaire-28 ($r = 0.62$, $P < 0.0001$). The ZBI has also been found to correlate well with the Global Index of Burden ($r = 0.71$) (Hébert et al., 2000). Less strong correlations were made between the ZBI and the Revised Memory and Behavioral Problems Checklist ($r = 0.53$, $P < 0.0001$) and the Dementia Management Strategies Scale ($r = 0.53$, $P < 0.0001$) (Nan, 2012). While these latter tools do not directly assess *burden*, these findings suggest that specific behavioral characteristics of the caregiver and care-recipient are associated with changes in ZBI scores.

Measures of test reliability have found the ZBI to be consistent with test-retest coefficients between 0.71 and 0.89 (Gallagher et al., 1985; Seng et al., 2010). While there seems to be internal consistency of the tool, Durme et al. (2012) suggest that much of the research conducted with the ZBI suffers from not having a well-designed definition of "informal caregiver". They propose that lack of such a definition in the literature presents a barrier to generalizing CB data due to the potential inconsistency of research subject characteristics and their comparability to actual patients.

ZBI Clinical Implementation & Limitations

The ZBI is available in over 70 different languages (Mapi Research Trust, 2014) and exists in several shortened versions. Due to the length of the 22-question version several researchers have made efforts to shorten the tool while preserving its subscales, validity, and reliability. One of the earliest, an 18-question version, created by Whitlatch, Zarit, and von Eye (1991) never became popular in either the clinical or research settings. A later 12-question

version (ZBI-12) received more attention due to its high correlation (0.92-0.97, $P < .001$) with the full-version (Bédard et al., 2001) and its validity for caregivers of care recipients with advanced conditions (i.e. cancer, dementia, & acquired brain injury) (Higginson, Gao, Jackson, Murray, & Harding, 2010). Interestingly, a Canadian national longitudinal study found the ZBI-12 to be more predictive of future caregiver dysphoric symptoms than the full-version (O'Rourke & Tuokko, 2003). This same study verified continuity of the two-factor structure (i.e. role strain & personal strain) in the ZBI-12.

Two additional screening versions have been developed with good correlation with the full version. These are the four-question (ZBI-4) (Bédard et al., 2001) and one-question (ZBI-1) (Higginson et al., 2010) versions. The ZBI-4 had higher Spearman correlation coefficients at 0.88-0.92 compared with the ZBI-1 at 0.68-0.78. Both tests had a higher than 80% sensitivity and 50% specificity for caregiver *burden* when compared to the full ZBI. These new screening versions and other shortened forms offer the clinician a more rapid way to assess CB without sacrificing validity.

Application of these or any version of the ZBI in clinical settings has historically been limited by the lack of well-defined interventional cutoffs. Early guidance by Zarit & Zarit (1987) proposed that *burden* be considered severe for scores between 61-88, moderate for scores between 41 and 60, mild for scores between 21 and 40, and little or absent for scores under 21. More recent research disputes these cutoffs and has shifted the interpretation of ZBI scores (Hébert et al., 2000; Bedard et al., 2001). Hébert et al. (2000) used data gathered from 312 Canadian caregivers. As ZBI scores were not normally distributed, non-parametric statistical analysis was used to determine distribution. They assumed scores falling in the lowest quartile represented lower levels of *burden* and scores in the highest quartile represented the highest level

of *burden*. Using this method they suggested the following change: low *burden* 0-8, moderate *burden* 9-17, high *burden* 18-32, and severe *burden* 33-88 (see Table 1). While this evidence changes our understanding of the distribution of ZBI scores across a population there has only been one study associating specific ZBI scores to clinically relevant diagnosis. This study by Schreiner, Morimoto, Arai, & Zarit (2006) found a ZBI score of 24 to have a 64% positive predictive value, and 72% negative predictive value for caregivers experiencing symptomatic depression.

Table 1: Hébert et al., (2000) Percentile Distribution of ZBI scores (N=312)

	Percentiles	22-Item ZBI Score (/88)	12-Item ZBI Score (/48)
Low	5 th	2.0	0.0
	10 th	4.0	0.0
	20 th	7.0	2.0
Moderate	25 th	9.3	3.0
	30 th	11.0	3.6
	40 th	14.0	5.0
High	50 th	18.5	8.0
	60 th	24.0	11.0
	70 th	30.0	15.0
Severe	75 th	33.0	18.0
	80 th	37.4	20.6
	90 th	46.0	26.0
	95 th	53.0	32.0

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Research has also broadened our understanding of clinically relevant cutoffs for the shorter ZBI versions. In the same Canadian study discussed earlier the ZBI-12 was found to have the following score distribution: low *burden* 0-3, moderate *burden* 3-8, high *burden* 9-18, and severe *burden* >18 (Hébert et al., 2000). Bédard et al. (2001) found similar distribution of the ZBI-12 across a larger population (N=413) and defined its highest quartile as >17 (see Table 2). They suggested that this number be used as an indicator of high *burden*, but research by O'Rourke & Tuokko (2003) found when looking at caregiver depression, this cutoff had low specificity and low sensitivity. Bédard et al. also assessed the ZBI-4 and determined the

following distribution: 25th percentile equal to one, 50th percentile equal to four, and 75th percentile equal to eight. No further research has been conducted to define a clinical cutoff for the ZBI-4. It is understood that the sensitivity and specificity of short-form versions of the ZBI are inversely related depending upon the specific questions withheld. As an example, if a question is removed from the full-version ZBI, and the statistical sensitivity increases compared to a population's average *burden* score, the specificity is likely to decrease (Higginson et al., 2010).

Table 2: Bédard et al., (2001) Percentile Distribution of ZBI scores (N=413)

Quartile	Percentile	22-Item Version	12-Item Version	4-Item Version
First	25 th	8	3	1
Second	50 th	18	9	4
Third	75 th	30	17	8

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These cutoffs and other research regarding CB use a diverse population of caregivers and this has led some researchers to question the generalizability of data concerning the topic of CB. Vitaliano, Young, and Heather (1991) questioned the heterogeneity of sample populations, citing caregiver differences such as marriage status, the presence of child dependents, and the caregiver's relationship to the care-recipient. They encourage data to be scrutinized for its applicability to specific populations and emphasized the perspective of role theory. This theory states that different expectations for giving and receiving care between specific individuals may lead to differences in stress perception related to the transfer of care (Hardy & Conway, 1978). This stress perception can be shaped by social role norms associated with marital dyads, parent-child dyads, or friend-care recipient dyads.

Other potential complications with using the ZBI for *burden* assessment arise from bias associated with the Likert format. These forms of bias include acquiescence bias, the tendency of respondents to agree with all questions or to indicate a positive connotation, midline bias, a

preference for choosing the central point or avoiding extremes on a scale, and socially desirable bias, the tendency of respondents to choose an answer based upon what they feel is socially acceptable or ethical (Greenleaf, 1992).

Current research has not addressed the effects of baseline caregiver depression on ZBI scores. This has the potential to induce artificially high scores and lead to inappropriate use of limited resources including caseworkers and caregiving classes. Within the clinical setting it is important for the healthcare provider (HCP) to be conscious of caregiver depression related to *burden*.

Organizational Problem & Project

The goal of this project is to assess CB using the ZBI-4 as a screening tool within an Alzheimer's and dementia center in Oregon. The choice of this screening tool was based upon the previously discussed research and the ZBI's wide validation in the literature. Further interest in this tool involved its brevity and its high correlation with the full-version ZBI.

The goal of the project is as follows: 1) meet with ancillary staff and technical support to decide upon a method for combining screening practices into workflow and develop a format for presentation of the data within the currently used EMR, 2) use previously discussed literature in order to define a clinic specific cutoff for intervention, 3) outline a provider plan of action for caregivers experiencing exceptional *burden*, and 4) develop a patient handout with information regarding available local and national caregiver resources.

Project Approach & Outline

This quality improvement project took place in an Oregon ADCC. The center provides direct care for patients with ADRD and supports research and education surrounding these

diagnoses. During the project, caregiver demographic information, which will be discussed in a later section, was collected to validate an interventional cutoff for ZBI-4 scores.

Participants & Data Protection

Participants in this project included caregivers of patients being seen at the ADCC between January 5th 2015 and March 30th 2015. Data collection was limited to caregivers between 21 and 89 years old who self-identified as a primary caregiver. While not every patient presented to the clinic with a caregiver, the presence or absence of a caregiver was understood to reflect the patient's caregiver dependence. The sample size was limited by the number of patients and caregivers visiting the clinic during the survey period. Data collected was manually de-identified by clinic staff before being stored in a locked office in the ADCC. Incomplete ZBI-4 forms were discarded.

Facilitators & Challenges

A significant facilitator of this project was the expressed interest of this ADCC's healthcare providers in transitioning to the ZBI. Staff were highly motivated to provide evidence based care to patients suffering from ADRD and their families. This motivation, along with the convenience of the EMR, was expected to greatly ease the introduction of this intervention into the clinic setting. Furthermore, ZBI in the clinical setting has been supported by research (Durme et al., 2012; Bédard et al., 2001; Rankin et al. 1994; Hébert et al., 2000).

Several potential barriers to this project were also identified. First, it was expected that introduction of new data fields to the EMR for documentation of ZBI-4 results might present a challenge due to the complexity and size of the EMR. Institutional technology support was enlisted to accomplish this task. Next, there was the goal of defining a ZBI cutoff that was appropriate to this institution's patient population. To assist in this effort, data from several of

the previously discussed studies were used to establish this definition. The ZBI-4 was used in the clinical setting for three months and results of actual caregivers were compared to the established cutoff. In this way, adequacy of the interventional cutoff for the caregiver population specific to this ADCC was determined.

Project Implementation

This project began with a department presentation outlining the validity of the ZBI-4 within a dementia caregiver population and describing the method by which ZBI-4 data were collected in the clinic. During this meeting a clinical cutoff for provider intervention was described. The project continued with the successful implementation of the logistical plan for assessing ZBI-4 scores.

Defining a Clinically Relevant Cutoff

Schreiner et al. (2006) suggested using a full-version ZBI score of 24 as a clinically significant cutoff for potential caregiver intervention. Considering the ZBI score distributions of the Bédard et al. (2001) and Hébert et al. (2000) studies, a score of 24 falls between the 50th and 75th percentiles. Using this as a reference, a score above the 50th percentile of ZBI-4 scores was recommended as a cutoff. This value was derived from the Bédard et al. (2001) distribution of ZBI-4 scores and was defined as a total of five. Understanding that neither the Bédard et al. (2001) nor the Hébert et al. (2000) studies fully represented caregiver or patient demographics at this ADCC a three-month review of ZBI-4 results following implementation of ZBI-4 caregiver assessment was proposed.

During this period, versions of the ZBI-4 including additional caregiver demographic questions were disbursed (Appendix A). The additional information included the caregiver's age, marital status, relationship with the care recipient, employment status, and designation as

primary caregiver. These demographics were collected to compare the ADCC population with the populations studied by Bédard et al. (2001) and Hébert et al. (2000). ZBI-4 results were interpreted using non-parametric statistical analysis for comparison with previously discussed studies. Caregiver demographic information was also analyzed for similarity with the comparison studies. The following statistics were determined: mean and distribution of caregiver age, percentage of male and female caregivers, percentage of self-identified relationships to care recipient (e.g. 50% spouse, 15% child of care recipient), and percentage married and employed. Using this data the established ZBI-4 cutoff was reevaluated.

Electronic Medical Record Smart Phrase

As an adjunct to this project, a smart phrase was created as a healthcare provider resource for caregivers experiencing increased levels of *burden*. A smart phrase is a standardized phrase or statement that may be easily added to the EMR for patient education or clinical documentation. This smart phrase was added to discharge paperwork of caregivers who scored above the predetermined ZBI-4 clinical cutoff. The smart phrase outlined community services and online resources for caregivers of patients with ADRD. The project center's case manager, along with the Oregon Alzheimer's Association and other resources, was enlisted to create this handout.

Goals & Outcome Evaluation

Completion of this project was determined to be the successful implementation of a logistical plan for assessing all caregivers at the proposed Oregon ADCC using the ZBI-4 and documentation of survey scores in the EMR. Additionally, a three-month assessment of caregiver ZBI-4 scores and demographics was completed to confirm validity of the clinical cutoff. Finally, a digital smart phrase and caregiver handout were created as resources for ADCC staff to share with clinic caregivers.

Implementation of the Project

The project began by meeting with clinic staff and outlining a plan for executing a new plan to assess caregivers with the chosen *burden* assessment tool. It was agreed that the MCSI was not adequate to evaluate CB. Not only was there no framework in place for conveying MCSI results to caregivers but also there was no guidance on interpreting test results. Due to its prominence in the literature there was already a preference for the ZBI. To verify that this was the best tool for caregiver assessment, a scholarly review of the literature was conducted outlining the statistical and logistical characteristics of these two tests. This review solidified the choice of the ZBI over the MCSI and also prompted the idea of using ZBI-4 short-form version. As described earlier, three studies were identified to aid in defining a clinically relevant cutoff for ZBI scores and translating the cutoff to the short form version. These studies include Hébert et al. (2000), Bédard et al. (2001), and Schreiner et al. (2006).

Once the clinical cutoff was determined, a survey including the ZBI-4 and specific caregiver demographic information was created (Appendix A). The demographic information gathered was chosen to reflect the same caregiver demographic information provided in the Hébert and Bédard studies. In this way, a comparison was drawn between this study population and the two comparison study populations. The project was approved by the OHSU IRB (study #IRB00011286) in December 2014 and data was collected January 5th through March 30th 2015. Upon the completion of the data collection phase, survey data were organized using the spreadsheet application Microsoft Excel and a statistical analysis was performed.

Outcomes in Relation to the Literature

In all, 60 surveys were completed. Of these, two were omitted due to incomplete data fields and 12 survey participants were not primary caregivers. These 12 fell outside inclusion criteria. No participants were excluded due to age. The remaining 46 surveys were included in the statistical analysis. The average age of the participants was 61.54 years old with the oldest being 89 and the youngest 31. The majority was female (28, 60.87%), married (40, 86.96%), and unemployed (25, 54.34%). Of the caregivers, the largest relationship groups were spouses (31, 28.26%) and daughters (seven, 15.22%). Table 3 provides a comparison of demographic information between this study data and the two comparison studies (Bédard et al., 2001; Hébert et al., 2000).

The greatest difference in mean caregiver ages was 8.69 years between the Hébert and Bédard studies. In both the Oregon ADCC and Hébert studies the majority of caregivers were female and unemployed. Additionally, throughout all studies the majority were married, but only in the Bédard study were the majority married to the care recipient. While caregivers were predominantly either spouses or children of the care recipient the specific proportion of these populations varied considerably.

Table 3: A Comparison of Caregiver Demographics Among Study Groups

	Oregon ADCC (N=46)	Hébert et al., 2000 (N=312)	Bédard et al., 2001 (N=413)
Mean Age	61.54 (sd=12.63)	69.7 (sd=13.4)	61.01 (sd=13.85)
Female	60.87% (n=28)	79.2%	
Married	86.96% (n=40)	69.1%	*62.5%
Unemployed	54.34% (n=25)	69.7%	
Relationship to Patient:			
Spouse	28.26% (n=31)	32.1%	62.5%
Daughter or Son (Natural or In-law)	26.08% (n=12)	48.6%	
Friend	6.52% (n=3)	8.9%	

*This number reflects only the percent of caregivers that were married to their care recipient. Actual percentage was not provided and may be higher when adding caregivers married to persons other than the care recipient.

The mean of ZBI-4 scores for the Oregon ADCC was 7.24 (sd=4.05). Seventy-eight percent of participants scored higher than the clinical cutoff of five. This mean falls at the upper limit of the second quartile of score distributions in the Bédard study. Internal consistency was calculated using Cronbach's Alpha to be 0.879 which was similar to the previously discussed internal consistency's calculated for the full question version ($\alpha=0.83$ and 0.93) (Majerovitz, 1995; Seng et al. 2010). Two demographic categories were selected and analyzed as independent variables affecting ZBI-4 scores. These included caregiver sex and employment status. Unpaired t-test analysis revealed female caregivers to have a statistically significant ($p=0.0089$) increased level of *burden* compared to their male counterparts. In contrast, the difference between unemployed and employed caregivers ZBI-4 scores was not found to be significant ($p=0.5652$). Table 4 presents average scores for these sub-samples and their standard deviation. Hébert et al. (2000) found no significant correlation between ZBI scores and sex or employment status.

Table 4: Mean ZBI-4 scores among sub-samples

	Mean Score	Standard Dev.
Female	8.5	3.72
Male	5.28	3.83
Employed	7.62	3.98
Unemployed	6.92	4.15

Discussion

This demographic comparison of research samples in this project revealed several constant characteristics of caregiver populations. The data revealed a mean caregiver age in the 7th decade of life. As the majority of caregivers are spouses or children of the care recipient, this consistency in mean age may reflect the average age of ADRD onset. If this average age was considerably younger we might expect the majority of caregivers to transition from spouses and children of care recipients to parents of care recipients. This average age of ADRD could also explain why the three sample populations under consideration are also characterized by being predominately married and unemployed as the prevalence of retirement and marriage increase with age (National Institute of Aging, 2007; Cohn, Passel, Wang, & Livingston, 2011). The difference in percentage distribution of caregiver relationship to care recipient may represent population variance or be reflective of sampling strategies. While the Oregon ADCC and Bédard studies were completed in institutional settings, the Hébert study was conducted using in home surveys collected through a national Canadian sample.

Analysis of the ADCC data revealed a statistically significant increase of female caregiver ZBI-4 scores. This may reflect the finding that female caregivers more often feel that they have no choice in becoming a caregiver and on average spend more time with their care recipient (Alzheimer's Association, 2014). Conversely, employment status was not found to be a significant predictor of ZBI-4 scores. This is interesting, as one may assume that the added *burden* of work may increase overall stress. This finding may not actually represent the

combined stress of caregiving and employment due to the lack of data addressing the actual number of hours study participants spent caregiving versus working.

The originally designated clinical cutoff for ZBI-4 scores was five. This cutoff was based on Schreiner et al. (2006) research suggesting increased rates of symptomatic depression when ZBI scores increased to about 24. This score was translated into a ZBI-4 cutoff using data collected by the two comparison studies. Interestingly, on average, ZBI-4 scores at this Oregon ADCC fell above the defined clinical cutoff with a mean of 7.24. There are several potential explanations for this observed increased level of *burden*. The sampling technique and small sample size may have produced a non-representative or skewed sample population. Patients and caregivers presenting to the ADCC may represent a population of patients experiencing greater levels of disease progression and caregiver stress. The initially determined cutoff based on the comparison of score distributions across the full and shortened ZBI versions may not be accurate. As mentioned previously, 78% of participants scored above the proposed interventional cutoff. If this cutoff were raised to seven, this percentage would fall to 50% of participants. This may be a more appropriate choice for a clinical cutoff as this score bridges the gap between the second and third quartiles of scores in the Bédard study and places the cut-off between what is described by Hébert and colleagues as being the difference between moderate *burden* and severe *burden*.

Practice-related implications/recommendations

The use of the 4-item ZBI in the Oregon ADCC demonstrated the potential to determine increased levels of caregiver *burden* and need for caregiver assistance and follow-up. This tool offered several potential benefits to the clinic that included increased provider awareness of caregiver *burden* and its use as a facilitator of conversations regarding caregiver resources and institutionalization of care recipients. Data collected during this study may also be used to

underline the clinics need to hire a case manager or to implement additional programs to support and train caregivers.

Following data analysis and reevaluation of ZBI-4 scores in this clinic setting the clinical cutoff should be increased from a score of five to a score of seven. To support this transition additional ZBI-4 data should be collected and analyzed across a larger sample population and compared to pertinent clinical endpoints. These may include higher rates of caregiver morbidity and mortality; depression symptoms or use of antidepressant medications; care recipient institutionalization or additional negative care recipient outcomes. Further study may also analyze specific predictors of ZBI-4 scores to identify potentially modifiable contributors to increased caregiver *burden* within this ADCC's population.

Conclusions

This project provided a foundation for the use of the 4-item ZBI assessment tool to be used in clinical settings as a determinate of caregiver *burden* within the Oregon ADCC. Implementation of this program at other sites may require adaptation to the specific population. Further research should be conducted to determine the appropriateness and applicability of this assessment plan to other dementia care centers or alternate care settings.

Summary

Using foundational research supporting the use of the ZBI-4 as a tool for assessment of caregiver *burden* and new data suggesting it may be used as a predictor of clinical depression symptoms, this assessment tool was chosen for use as part of routine assessment of caregiver *burden* in an Oregon ADCC. Data collected during this study aided in determining a clinically relevant cutoff for ZBI-4 scores of seven. Further evaluation of this cutoff is recommended through continued assessment of caregivers and additional clinically relevant outcomes. This and

further data will be beneficial in producing support systems and programs to improve the health of community caregivers, their ability to provide for their care recipient, and reduce overall healthcare costs by avoiding care recipient institutionalization and other adverse outcomes associated with increased caregiver *burden*.

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Appendix A

Caregiver Name: _____

For Staff Use Only: Patient I.D. # _____

Caregivers Age: _____ Sex: M F

What is your relationship to this patient (please circle one):

Spouse Significant Other Son/Daughter Friend Other: _____

Are you currently married: Y or N

Are you currently employed: Y or N

Would you describe yourself as the primary caregiver to this patient: Y or N

Please Circle the Response that best describes how you feel.

	Never	Rarely	Sometimes	Frequently	Nearly Always
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
Do you feel strained when you are around your relatives?	0	1	2	3	4
Do you feel uncertain about what to do about your relative?	0	1	2	3	4
Total Score (out of 16) _____					