Caring for the Caregiver

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Abstract

Background: As the nation's population ages and the prevalence of chronic diseases, like dementia, increases, informal caregivers will play an increasingly important role in maintaining independence for the elderly. Informal caregivers provide most long-term care for the elderly in this country and save hundreds of billions of dollars in healthcare costs annually. However, most informal caregivers experience burden secondary to caregiving that adversely impacts their physical, social, and/or psychological health. Caregiver burden threatens caregiver health and contributes to institutionalization of care recipients. Since the program of all-inclusive care for the elderly (PACE) model of care delivery relies heavily on informal caregivers to maintain independent aging, understanding and meeting the needs of caregivers is essential to the sustainability and success of PACE programs. **Purpose:** This evidence-based practice (EBP) project was a gap analysis that surveyed 156 caregivers at an urban PACE program in the Midwest to examine caregiver demographics, caregiver burden, caregiver interest in support services, and the relationship between these variables to guide the development of caregiver programs. **Methods:** *Caregiver Assessments* were administered to 156 caregivers via telephone or in person. The assessment included caregiver demographics, interest in caregiver services, and the 12-item *Zarit Burden Interview (ZBI-12*) to assess caregiver burden. The *ZBI-12* has good reliability and validity as indicated by a Cronbach's alpha of 0.88 and a correlation with the full version *ZBI* scores of 0.95. Results were analyzed using descriptive statistics, the Pearson r correlation test, the Wilcoxon signed rank test, and the Mann-Whitney U test on SPSS version 25. This project was approved by the Arizona State University IRB. **Results/Outcomes:** Of 171 eligible informal caregivers of program participants living outside of an institution, 156 completed the survey, 3 refused, and 12 were unreachable. Most informal caregivers surveyed were Caucasian (69.5%) females (66%), children of the care recipients (45.5%), caring for people with dementia (40.6%), with some college education (37.2%), who earned $10,000-$25,000 annually (38.7%), provided over 30 hours of care per week (55.8%), and averaged 61.4 years old (*SD*=7.7). The average *ZBI-12* score was 12.15 (*SD*=9.04), indicating a moderate level of burden. The most common stressors indicated by caregivers were activities of daily living (ADL) assistance (63.5%) and the time commitment involved in caregiving (57.7%). Correlates to high burden score included: limited time, aggressive behavior, financial stress, grief, assistance with ADLs, wandering behavior, toileting assistance/incontinence, and lack of sleep. Respite care was identified by 42.9% of those surveyed as the most helpful resource provided by PACE. 55.1% and 50.6% of caregivers indicated an interest in educational sessions and support groups respectively, if these services were offered in the future. **Conclusion:** Through the exploration of caregiver demographics, factors correlated to increased burden, and caregiver interest in support services, the results from this EBP project provide guidance to programs, particularly other PACE programs, seeking to proactively mitigate caregiver burden through support services. The results indicate that respite care, educational sessions, and support groups should be prioritized when developing informal caregiver support services.

Caregiver burden is a complex phenomenon that incorporates the physical, psychological, and psychosocial consequences of providing care (van der Lee, Bakker, Duivenvoorden, & Droes, 2014). While caregiver burden can affect anyone delivering care, prevalence rates are higher among informal caregivers assisting people with dementia (PwD)(Alzheimer's Association, 2017). Given that caregiver burden is a common precursor to institutionalization, reducing the prevalence among those helping PwD is a public health priority that will improve patient quality of life, protect informal caregiver health, and save the nation billions of dollars in care giving costs (Alzheimer's Association, 2017).

This evidence-based gap analysis examines the way organizations can assess and mitigate caregiver burden to preserve independent living in the geriatric community. While the focus of the literature review and evidence synthesis pertains to caregivers of PwD, the gap analysis examines the demographics, burden levels, and support service interest of primary caregivers for elderly individuals with a range of medical diagnoses. The design of the gap analysis and the results can be used by healthcare organizations attempting to better meet the needs of the informal caregivers they serve.

Background & Significance

Alzheimer's dementia is the most common cause of dementia, accounting for 60 to 80% of cases; therefore, in this paper, Alzheimer's disease and dementia will be used interchangeably. It is estimated that by 2050, one person will be diagnosed every 33 seconds (Alzheimer's Association, 2017). The result is a projected 13.8 million people with Alzheimer's disease in the United States (U.S.) by mid-century. This is more than double current prevalence.

Informal caregivers of PwD are more likely than those caring for people without dementia to: provide assistance with three or more ADLs; monitor the health of the care recipient; help with mobility; manage finances; manage mental or emotional health problems; coordinate healthcare; and arrange for outside services (National Alliance for Caregiving & AARP, 2015; U.S. Department of Health and Human Services, 2014). Given the quantity of tasks that require assistance and the duration of the disease process, it is not surprising that those providing care for PwD provide more than double the hours of care annually for more years than informal caregivers of those without dementia (Alzheimer's Association, 2017; National Alliance for Caregiving & AARP, 2015; U.S. Department of Health and Human Services, 2014).

Family members care for the majority of PwD at home. These family caregivers serve as the cornerstone of maintaining independent placement for these individuals (Alzheimer's Disease International, 2015). It is estimated that in 2016, family caregivers saved the U.S. over $230 billion in healthcare services (Alzheimer's Association, 2017). This number will only rise in the coming years as rates of dementia increase. Unfortunately, caregivers of PwD face significant rates of caregiver burden, which negatively affect their abilities to continue caring for loved ones. Compared to caregivers of those without dementia, informal dementia caregivers report higher rates of financial stress, emotional stress, depression, anxiety, cognitive decline, physical strain, frailty, sleep disturbances, and a lower quality of life (Alzheimer's Association, 2016; Bremer et al., 2015; Dassel & Carr, 2016; Fonareva & Oken, 2014; Goren, Montgomery, Kahle-Wrobleski, Nakamura, & Ueda, 2016; National Alliance for Caregiving & AARP, 2015; Valimaki et al., 2016; von Kanel et al., 2014).

Caregiver burden is a construct that incorporates the subjective and objective physical, psychological, and psychosocial impacts of providing daily services (van der Lee et al., 2014). High rates of informal caregiver burden significantly contribute to institutionalization of PwD (Afram et al., 2014). Despite the substantial demands on informal dementia caregivers and the importance of the role these caregivers play in the healthcare system, providers tend to neglect their needs. Only 32% of caregivers report that healthcare providers asked them what they needed to provide care to the recipient and only 16% report that providers inquired about what caregivers need to maintain self-care (National Alliance for Caregiving & AARP, 2015).

While traditional healthcare delivery formats routinely fall short of addressing the complex needs of PwD and their caregivers, innovative programs across the country are attempting to change these dismal trends by addressing patient and caregiver needs using a more holistic approach (Alzheimer's Association, 2017). Programs of all-inclusive care for the elderly (PACEs) are an example of a comprehensive care delivery system attempting to better meet the needs of patients and their families in the face of an aging population and currently unsustainable national healthcare expenditures (Beauchamp, Cheh, Schmitz, Kemper, & Hall, 2008). PACEs are participant-centered and use an interdisciplinary approach to provide high quality care for the elderly and disabled. These programs use a set monthly reimbursement per program participant from Medicaid, Medicare, and/or private funds to provide all-inclusive care including but not limited to: medical services, housing in assisted living facilities (ALFs) or skilled nursing facilities (SNFs), geriatric psychological care, physical and occupational therapies, speech therapies, recreational services, home health care, care coordinator, and dietary services (Beauchamp et al., 2008). According to a Centers for Medicare & Medicaid Services' (CMS) report, PACEs improve healthcare outcomes, reduce hospital use, increase preventative care, decrease depressive symptoms, improve self-reported health status, and maintain the functioning of those enrolled (Beauchamp et al., 2008).

A PACE located in the Midwestern U.S. identified the high utilization of ALFs as an area for improvement within their organization. In 2017, approximately 24% of this organization's participants were enrolled in ALFs compared to the national average of approximately 15% within other PACE programs. The monthly cost of ALF placement represents approximately 11% of the organizations monthly operating funds. The high ALF placement rate is detrimental to the organization, decreases funds for services to maintain independent placement, is contrary to the organizational mission of maintaining independent living, and often decreases the quality of life for participants.

In 2017, nine out of the eleven participants transitioned to a higher level of care had a primary diagnosis of dementia or cognitive decline. All cases were impacted by caregiver limitations and eight of the cases cited caregiver stress as a significant precipitating factor to placement. Of the 306 members at this PACE, 60.7% have a dementia related diagnosis. Participants with dementia related diagnoses are more likely to be living in an ALF than the general PACE population with a 28% and 23% ALF placement respectively. Interviews with multidisciplinary employees at the organization indicate that caregiver burnout is a significant cause of ALF placement.

Problem Statement and PICOT Question

Informal caregivers provide a significant service to PwD and the community as a whole. Their care and dedication maximizes independent functioning and saves the U.S. healthcare system billions of dollars annually. Caregiver burden increases institutionalization among PwD and is extremely costly to the healthcare system if it is not prevented and properly managed. As the nation confronts the growing prevalence of dementia within an aging population, interventions to bolster informal caregivers will become an increasingly important aspect of community health. The efforts at the Midwestern PACE program to maintain community placement among PwD by decreasing caregiver burden is reflective of a larger societal need.

This discussion leads to the following PICOT question: For primary caregivers of PwD (P), what multidisciplinary interventions (I) can be used to prevent caregiver burden (O) when compared to standard care (C)?

Search Strategies

A thorough review of the most current evidence took place to answer the PICOT question. Four databases were extensively searched – PubMed, PsychINFO, CINAHL, and the Cochrane Database. These databases were selected for their relevancy to the topics of caregiver burden and PwD. Additionally, these databases are known for their rigor and contributions to the medical field.

The databases were searched using combinations of the key terms that addressed all aspects of the PICOT question and included: *dementia*, *Alzheimer's disease*, *informal caregiver*, *family caregiver*, *spouse caregivers*, and *family*. Key terms for the intervention did not include *multidisciplinary* because this narrowed the search too significantly. Instead operational forms of multidisciplinary interventions were used and included the terms: *education*, *support group*, *prevent*, and *social support*. The outcome was specified using the terms: *caregiver burden*, *compassion fatigue*, *caregiver burnout, burden*, and *depression.* Filters applied included date of publication (2013 to 2018), English language, and peer-review journal articles. Mesh and Boolean terms were to broaden the search. The titles and abstracts of all articles were assessed for searches yielding under 200 results.

An initial search of PubMed using key terms *family caregiver, dementia, caregiver burnout,* and *prevent* yielded only one result so Mesh terms were added and the key terms were made less specific to widen the search. This search yielded 872 results so further search terms specifying the *dementia* population were added. Filters were added to further limit the search.

Additional searches yielded 200-20 results.

The initial search of PyschINFO included the key terms *caregiver burnout*, *dementia*, and *family* and yielded only eight results. The search terms were changed to *family caregiver* and *dementia.* This search yielded 288 results so the above filters were applied to limit the results.

The initial CINAHL search included the key terms *caregiver burnout, dementia*, and *family*. As with the other database searches, initial results were limited and only produced one article. Changing the term *caregiver burnout* to *caregiver burden* significantly increased the search results to 298. Filters were applied to this search to lower the article count to 123 results.

One of the initial Cochrane Library searches included the terms *caregiver burnout* and *dementia* produced a limited two results. Adding the search terms *family caregiver* and *Alzheimer's* increased these article results to 33. Given the rigor of systematic reviews included on Cochrane Library, it is not surprising that these searches yielded fewer results than those completed on other databases.

Reviewing the titles and abstracts of the articles identified in these database searches yielded 51 relevant studies. Additionally, the reference lists of these articles were scanned to identify 10 other important studies. Full text copies of the 61 relevant studies were attained and reviewed. Rapid critical appraisal checklists as well as outlined inclusion and exclusion criteria were used to narrow the article pool down to the 10 most relevant and highest quality studies. These included four randomized control trials, four systematic reviews, one longitudinal study, and one mixed method trial (Appendix A).

Inclusion criteria included interventions targeting informal caregivers of PwD living at home. Exclusion criteria included interventions targeting PwD only and formal caregivers. Since numerous systematic reviews (SR) were identified, the studies included in the SRs were compared. If more than half of the studies included overlapped, one of the SRs would be removed to minimize the risk of representing certain study results twice. Lastly, for the purpose of selecting the final 10 articles to be included in the table, preference was given to higher levels of evidence. For example, rigorous SRs and randomized control trails (RCTs) were selected over studies with qualitative designs.

Evidence Synthesis

The Melnyk and Fineout-Overholt's (2011) rapid critical appraisal was used to evaluate the quality of the 10 articles selected for the literature review. The majority of the studies were high-level evidence, including four SRs and four RCTs (Appendix A). The remaining two articles included a non-randomized non-controlled longitudinal study and a mixed method study (Appendix A). Only three of the 10 articles reported their funding source; however, no bias was recognized in any of the studies. All of studies had an adequate sample size. Marim et al. (2013) was a SR of RCTs that only included four studies. However, this is appropriate given the strict inclusion criteria and specification of the measurement tool used. The literature review includes an international sampling, with only two studies originating in the U.S. (Appendix A). All of the interventions were executed in a community setting and addressed the needs of those providing care to community-dwelling PwD (Appendix B).

Eight out of nine studies that measured caregiver burden found a significant decrease or a moderate to strong level of evidence suggesting a decrease following the interventions (Appendix A). Since all of these studies included some form of structured education, it is reasonable to assume education contributed to these improvements. However, due to the heterogeneity of the education provided it is difficulty to draw a conclusion regarding which type of education is most beneficial. For example, the Ducharme et al. (2015) study indicates that while structured education contributes to caregiver psychological improvements, an education booster six months after the initial intervention does not significantly improve outcomes (Appendix A). Strong reliability and validity can be assumed for all the selected studies due to the high-quality measurement tools, the rigorous methodology, and the prevalence of statistically significant results (Appendix B).

As the U.S. healthcare system strains under the demands of an aging population, preventing caregiver burden to maintain community-dwelling among PwD is a national priority. This literature review demonstrates the range of interventions being explored to address caregiver burden. While there are numerous approaches to combat caregiver burden, current evidence suggests that structured education is an essential and effective component of any program intended to augment burden among caregivers (Appendix B). The studies in this literature review also provide evidence that support groups, skills training, CBT, and interdisciplinary management may improve quality of life, decrease burden, and decrease psychological distress among caregivers of PwD (Appendix B).

For the Midwestern PACE, or any organization hoping to proactively manage informal caregiver burden, an essential first step is understanding the caregiver population served. Therefore, prior to developing caregiver services, like the structured educational sessions supported in the literature review, a comprehensive assessment of the informal caregiver population is necessary to evaluate: current caregiver burden levels, caregiver demographics, caregiver interest in services, and which caregivers within the organization are at the greatest risk for burden.

While the literature states and previous internal evidence indicates that burden is most significant among caregivers of PwD, when assessing the informal caregiver population served by an organization, all caregivers of those who are not currently institutionalized should be included so that the organization can get a holistic picture of caregiver needs. This is important because services developed by the PACE are likely to serve the caregivers of those with various diagnoses, not just those assisting PwD. Additionally, assessing the entire informal caregiver population is important to determine whether the trends of higher caregiver burden among those caring for PwD is true within the organization. This cannot be assessed unless there is benchmark data from informal caregivers assisting participants with a variety of disease processes, not just dementia. For these reasons, the *Caring for the Caregiver* project included all eligible informal caregivers within the PACE community, not just those serving PwD.

Purpose Statement

The purpose of this gap analysis was to better understand the informal caregivers served by a Midwestern PACE so the organization can develop informal caregiver support services. These services would reflect the needs of the caregivers and the evidence brought forth in the literature review regarding the most effective caregiver interventions. The future programs developed by the organization are intended to decrease caregiver burden and decrease institutionalization of program participants; this would benefit the program participants, their informal caregivers, and the organization alike.

Since most of the PACE participants have dementia, the focus of the literature review was on reducing burden among informal caregivers of PwD. However, all informal caregivers served by the PACE organization were assessed in this project because all caregivers would have access to future support services. In this evidence-based practice (EBP) project, caregivers completed the *Caregiver Assessment* (*CA*) at an urban PACE program in the Midwest to examine caregiver demographics, caregiver burden, caregiver interest in support services, and the relationship between these variables to guide the development of caregiver programs (Appendix C).

Organizational culture and attitudes regarding change initiatives among the staff was assessed at two sites before and after the intervention using the *Organizational Readiness for Change Assessment* (*ORCA*) (Appendix D). This data provided feedback regarding the impact of the intervention on staff attitudes. Additionally, the information about potential barriers to change served as a tool for PACE leadership when designing future programs or initiatives. Lastly, the assessment data provided insight into site strengths and weaknesses as perceived by the staff.

Conceptual Framework and EBP Model

Frameworks and theories guide change by presenting areas for improvement and conceptual relationships in an organized manner (Smith & Liehr, 2014). Dr. Barry Johnson (1996) developed the conceptual model *Polarity Thinking*, which proposed that seemingly opposed values work together to reach a greater purpose. The *Polarity Map* is a visual representation of *Polarity Thinking* (Appendix E). The model suggests that to attain a goal both values need to be leveraged and optimized. Neglecting one pole or the other will lead to a loss of the greater purpose (Johnson, 1996).

When applied to the PACE model and caregiver burden, *Polarity Thinking* suggests that to attain the greater purpose of maintaining independent living among participants, two seemingly opposed poles – the needs of the caregiver and the needs of the care recipient – must to be optimized. If either pole is neglected, the result will be a loss of the greater purpose and subsequent ALF or SNF placement for the PACE participant. While the traditional PACE model provides holistic care delivery to participant, care of the family caregiver is not directly incorporated into the program design (Beauchamp et al., 2008). Upon initial assessment of internal evidence at the Midwestern PACE, it appeared that a failure to address caregiver needs and the subsequent caregiver burden contributed to high rates of institutionalization among program participants. Utilization of the *Polarity Thinking* framework helped map and monitor pole management during intervention and subsequent program development.

The *Star Model of Knowledge Transformation* (Appendix F) was selected to further guide EBP implementation process (Stevens, 2012). The *Star Model* outlines five essential steps in evidence implementation and guides translation into practice. The cyclical nature of the *Star Model* promotes constant reevaluation (Stevens, 2012). This aligns with the *Polarity Thinking* framework where organizations are continually reassessed using the *Polarity Map* (Appendix E). Additionally, the *Star Model* incorporates new concepts while building upon old concepts (Stevens, 2012). This is consistent with the *Polarity Thinking* concept of supporting seemingly opposed values – the needs of the caregiver and the needs of care recipients - to achieve the higher goal of avoiding institutionalization. Incorporating the original value of providing high quality care to the participant while incorporating the new concept of assisting the caregiver optimizes goal achievement and decreases resistance to change within the organization.

Project Methods

This EBP project included the evidence summary, translation to guidelines, practice integration, and outcome evaluation steps of the *Star Model of Knowledge Transformation* to help the PACE better leverage the “needs of the caregiver-needs of the care recipient” polarity (Appendix E & F). The goal of this gap analysis was to better understand the PACE’s informal caregivers, their needs, how well the organization is currently leveraging the “needs of the caregiver” pole, and how they could better leverage the pole through future program development (Appendix E). The gap analysis and practice change occurred from September 2018 to March 2019 at two sites of an the urban, Midwestern PACE. The EBP project was designed in close collaboration with the PACE leadership team, specifically, the clinical director, the directors of interdisciplinary operations from both sites, the geriatric psychologist, and the social workers.

This EBP project consisted of three major steps: a staff educational session and pre-intervention *ORCA*; administration of the *CA* to all eligible informal caregivers; and a staff session to review the results and complete the post-intervention *ORCA*. Participants in the project included PACE staff and the eligible informal caregivers of PACE participants. Staff were provided a paper copy of the consent prior to participant and informal caregivers were either given a hard copy of the consent or informed of the consent over the phone. Staff and informal caregivers provided consent when they completed the assessments. All surveys (*CA* and *ORCA*) were deidentified, secured in a locked cabinet prior to data entry, destroyed following data entry, and kept in a password protected computer following entry into SPSS version 25. Cost of this intervention was minimal since the DNP student provided the majority of the labor but costs included: paper and ink for surveys; IDT member time for the initial educational session and the final results review sessions; social worker time for *CA* administration; and leadership time for the final executive summary presentation. The project was approved by the Arizona Institutional Review Board in 2018 prior to project initiation.

Staff Education and Pre-Intervention Assessment

Prior to any process change or program implementation, ensuring team buy-in is essential. Without a team that understands the purpose of a change and feels their input has been solicited, any intervention is likely to fail (Dawson & Andriopoulos, 2014). Therefore, a critical first step of process change is early staff involvement.

The first steps in this intervention were two all staff educational sessions that occurred at both the organization sites in September 2018. The purpose of these sessions was to: educate members of the team about caregiver burden, discuss the impact of caregiver burden on the PACE program, highlight the organization's goal to better mitigate caregiver burden, and outline the gap analysis that was being conducted from September 2018 thru January 2019 to better understand the informal caregivers. The educational session increased staff buy-in and provided staff a time to ask questions or express concerns pertaining to the purposed intervention.

An hour-long session was held at each PACE site. All members of the interdisciplinary team (IDT) were required to attend these meetings unless they were providing direct patient care during the session time. Twenty-seven staff members attended the session at one site and eleven attended the meeting at the other site. The differences in attendance were consistent with differences in organization size at the two sites. Attendees included: a psychologist, physician assistants, a nurse practitioner, physicians, physical therapists, occupational therapists, speech pathologists, transportation staff, pharmacists, social workers, nurses, dietitians, home health coordinators, and management staff.

Staff at the educational sessions were requested to complete the pre-intervention *ORCA*. The *ORCA* is a 62-item Likert scale that takes roughly 15 minutes to complete (Helfrich, Li, Sharp, & Sales, 2009) (Appendix D). The *ORCA* assesses staff perceptions pertaining to organizational culture and facilitation of change initiatives. The Cronbach's alpha is 0.95 and 0.85 for the facilitation and context subscales of the *ORCA*, respectively (Helfrich et al., 2009). Content validity was confirmed by a delphi panel of 160 volunteers with expertise in the field of implementation science (Veterans Health Administration, 2013).

Administration of the *ORCA* pre- and post-intervention helped assess any changes in staff attitudes during the intervention and allowed for a comparison of staff attitudes between the two organization sites (Helfrich et al., 2009). Pre- and post-intervention *ORCA* scores were analyzed in SPSS version 25 using the Wilcoxon signed rank test. *ORCA* data was compared between the two sites using the Mann-Whitney test.

Assessment of Informal Caregiver

Immediately following the staff educational sessions, the informal caregiver assessments started. Assessment of the caregivers using the *CA* occurred from September 2018 to January 2019 (Appendix C). Eligible caregivers were the primary caregivers of noninstitutionalized (in a SNF or ALF) PACE program participants. Primary caregivers were identified using participant charts and their status as the primary caregivers was affirmed by the social workers prior to caregiver contact. Some noninstitutionalized PACE participants did not have a caregiver; therefore, no caregiver could be contacted for this gap analysis.

Caregivers were contacted via telephone or in person by members of the social work team and the DNP student. Caregivers were then provided brief education about caregiver burden, informed about the PACE's caregiver initiative, and asked to participate by completing the *CA* (Appendix C). If they consented to participation, the survey was then completed with the assistance of a social worker, the DNP student, or independently by the caregiver. All surveys were completed in a private setting. Completion of the survey took ten to forty-five minutes depending on the among of elaboration that was provided by the caregiver during the process.

The *CA* is a survey that consists of three sections: a demographic section, the 12-item *Zarit Burden Interview* (*ZBI-12*) to assess burden level, and questions regarding interest in caregiver support services (Appendix C). The *ZBI-12* was selected because it has been found to be the most valid short version of the *ZBI* among caregivers of people with advanced conditions, which represents nearly all PACE participants (Higginson, Gao, Jackson, Murray, & Harding, 2010).The *ZBI-12* has good reliability and validity as indicated by a Cronbach's alpha of 0.88 and a correlation with the full version ZBI scores of 0.95 (Bedard et. al, 2001).

If the caregiver was determined to have a high burden during the survey (a *ZBI-12* score ≥ 17), they were offered a caregiver resource guide that listed available support groups within the area, educational sessions in the community, educational websites, and books about caregiving. Additionally, they were reminded about the services currently available at the PACE (primarily, respite care and home environmental modifications) and asked if there was anything the IDT could do currently to better assist them. These needs were relayed to the team. Lastly, the social worker assigned to work with the caregiver's PACE participant was notified of the high burden score.

SPSS version 25 was used to determine the *CA* descriptive statistics. The Pearson r correlation test was run to identify significant relationships between burden level and demographic variables. Lastly, the independent samples t-test was used to analyze responses between the two organization sites.

Dissemination and Post-Intervention Assessment

Following the final *CA* completion in January 2019, results were analyzed in February. In March 2019, a follow up meeting occurred with staff at both PACE sites to review the results, discuss clinical implications, outline recommendations for the organization moving forward, and administer the post-intervention *ORCA*. These sessions were an hour each and attendance was required by all IDT members who were not providing direct participant care during the scheduled time. Attendees included the same IDT members listed for the initial educational session.

Following the completion of the post-intervention *ORCA* by IDT staff, a comprehensive analysis of *ORCA* and *CA* results was completed. In April 2019, a leadership meeting was held with the organization's executive director, the chief operating officer, the clinical director, the directors of interdisciplinary operations for both sites, the quality manager, and the geriatric psychologist. During the leadership meeting an executive summary of the gap analysis was provided. Primary outcomes and recommendations for the organization moving forward were discussed.

Project Results

CA Results

From September 2018 to January 2019, 156 of 171 eligible caregiver completed the *CA*, 47 at the smaller site and 107 at the larger site, indicating a 91.2% completion rate. Three caregivers declined to participate and twelve were unable to be reached after over a dozen phone calls. Most of the respondents were Caucasian (69.5%) females (66%) with less than a college degree (66%) who were children of the care recipient (45.5%) and approximately 61 years old. Most of the caregivers surveyed earned less than $26K a year (48.6%), were not working (55.9%), and provide over 30 hours of care per week (55.8%) to a demented care recipient (40.6%). The most common stressors identified were providing ADL assistance (63.5%) and like there is not enough time to manage individual needs as well as care recipient needs (57.7%).

Descriptive statistics parametric tests were used to analyze the data. This project is like an exploratory pilot study to generate a hypothesis. For the purposes of the *CA* data analysis, due to the importance of detecting small to moderate differences with a small sample size (*p*-values >0.05 but <0.10 are referred to as trend), significance was tested at the p <0.10 (Woods, Lentz, Mitchell, Heitkemper & Shaver, 1997).

The average burden score on the *ZBI-12* was 12.15 (*SD*=9.04) and the scores ranged from 0 to 48 in both groups (*N*=156). This score indicates a moderate level of burden (Bedard et. al, 2001). There was a statistically significant difference between caregiver burden at the smaller organization site (*M*=14.02, *SD*=10.46) and the larger organization site (*M*=11.34, *SD*=8.28), *t*(154) = -1.71, *p*=0.089. The listed caregiver demographics were significantly different: education, *t*(154) = -2.77, *p*=0.006; annual household income, *t*(62.91) = -2.85, *p*=0.006; and caregiver race , *t*(52.60) = -3.15, *p*=0.003. The smaller site was more educated, earned more, and were more likely to be mixed race (as opposed to Caucasian or African American) than the larger site.

Additionally, while not statistically significant, the smaller site had more caregivers who work outside of the house (*M*=1.87, *SD*=1.01) than larger site (*M*=1.79, *SD*=1.03). Additionally, more caregivers at the smaller PACE site have dependents (*M*=1.61, *SD*=0.49) than caregivers at the larger site (*M*=1.67, *SD*=0.47). These numbers could help explain the significantly higher rates of burden at the smaller site because research shows those working or parenting are more likely to experience caregiver burden. Earning them the term the “sandwich generation” that highlights the pressure of numerous responsibilities to multiple generations. Table 3 outlines which caregivers were found to have the highest burden scores by key demographics variable like gender, race, age, and relation to care recipient (Appendix G).

The Pearson r correlation test was used to determine what demographic variables were correlated with a high *ZBI-12* score. The strength of the relationship (r) rangers from -1 to +1 with r < 0.3 indicating a weak correlation, r of 0.3-0.5 indicating a moderate correlation, r>0.5 indicating a strong correlation, and r of 0 indicates no correlation (Grove & Cipher, 2017). The following stressors identified by the caregivers were found to have a weak correlation to the total *ZBI-12* score: aggressive behavior by the care recipient, $r(154) = 0.29$, $p < 0.00$; financial stress, $r(154) = 0.29$, $p < 0.00$; grief, $r(154) = 0.27$, $p < 0.00$; providing ADL assistance, $r(154) = 0.26$, $p < 0.00$; care recipient with wandering behavior, $r(154) = 0.16$, $p = 0.05$; and providing toileting assistance/incontinence, $r(154) = 0.27$, $p < 0.00$. The stressors of limited time, $r(154) = 0.37$, $p < 0.00$, and lack of sleep, $r(154) = 0.30$, $p < 0.00$, were found to have a moderate correlation to the total *ZBI-12* score.

One of the primary goals of this gap analysis was for the PACE to learn more about informal caregivers' interest in support services. When provided a list of services currently offered by PACE as well as services PACE does not offer but is considering offering in the future, respite care was the most commonly selected service with 42.9% (*n*=67) of those surveyed selecting this as a service that would help. Home modifications were the second most common service selected with 34% (*n*=53) of respondents saying this would help. Respite care and home modifications are already provided by the PACE.

However, caregivers also indicated an interest in services that are not currently offered at the PACE. Support groups and educational sessions were the third and fourth most common service selected with 16.7% (*n*=26) and 15.4% (*n*=24) of respondents selecting these respectively. Additionally, 55.1% (n=86) and 50.6% (n=76) of caregivers reported that they would be interest in educational sessions and support groups respectively, if they were offered at PACE. Table 2 outlines which caregivers were found to be interested in educational sessions and support groups by key demographics variable like gender, race, age, and relation to care recipient (Appendix G).

ORCA **Results**

Twenty-four staff completed the pre- and post-intervention *ORCA* – 7 at the smaller site and 17 at the larger site. For analyzing *ORCA* results, the level of significance was changed to $p < 0.05$ rather than the $p < 0.10$ set for analysis of the *CA*. This change was made because more significant results with stronger relationships exist in the *ORCA* data.

Numerous statistically significant differences in the assessment indicate a difference in the context and facilitation domains at the two sites. Seven of twenty-three items in the context section of the assessment and eleven of thirty-nine items in the facilitation section were found to be significantly different between the two sites. All the significant differences were caused by higher scores at the smaller site. These higher scores indicate greater support, a better culture, and more facilitation surrounding change initiatives at the smaller PACE site.

While there were significant differences between scores at the two sites, there were no statistically significant differences found between the pre- and post-intervention *ORCA* results. This suggests that the intervention did not change staff member's attitudes surrounding change in the organization. Perceptions regarding context, facilitation, culture, and change were consistent before and after the intervention.

Discussion

The results indicate which informal caregivers may be at the greatest risk for burden within the PACE community (Appendix G). Certain demographic groups found to have the highest burden level were supported in previous research. Females were seen to have higher burden levels in this EBP and this has been demonstrated in previous research (Chiao, Wu, & Hsiao, 2015; Park, Sung, Kim, Kim, & Lee, 2015). Additionally, a spousal relation to the care recipient has previously been linked to a higher burden risk.

However, the results from this study conflict with previous literature with regards to the educational level and income level of those caregivers at the greatest risk for burden. Previous studies have indicated informal caregivers with lower educational and income levels are at the greatest risk for burden (Chiao et al., 2015; Park et al., 2015). However, the results of this gap analysis demonstrate that caregivers with a college degree and an income between $56,000 and $85,000 annually experienced the highest rates of burden. While initially surprising, these variables could be linked to caregiver employment status and the stress well documented within the “sandwich generation” (Do, Cohen, & Brown, 2014). While most research indicates those with a low annual income are at a greater risk for burden, a study by Do et al. (2014) supported the results of this EBP when they found that those in earning $50,000 to $75,000 a year experienced most burden. Adults in middle age (40-64 y.o.) demonstrating the highest rates of caregiver burden is also consistent with the “sandwich generation” being at the greatest risk for burden (Do et al., 2014; Erickson, n.d.).

Lastly, the results of this gap analysis differ from previous research because the caregivers of those with congestive heart failure and type II diabetes were found to experience greater burden than those caring for PwD. Numerous studies have found those caring for PwD experience more adverse outcomes secondary to caregiving than those caring for people with other disease processes (Alzheimer’s Association, 2016; Bremer et al., 2015; Dassel & Carr, 2016; Fonareva & Oken, 2014; Goren et al., 2016; National Alliance for Caregiving & AARP, 2015; Valimaki et al., 2016; von Kanel et al., 2014). The caregivers of PwD in this gap analysis may have lower burden levels because of the respite services and day center attendance provided by the PACE. Additionally, since more participants with dementia are already residing in ALF and SNF programs than PACE participants with other diagnoses, it is possible that the informal caregivers of PwD experiencing high burden have already had the care recipients institutionalized.

Lastly, the informal caregiver stressors that were found to correlate with burden in this analysis were like those found in previous studies. Aggressive behavior by the care recipient, the provision of ADL assistance, wandering behavior by the care recipient, and a lack of sleep for the caregiver were found to correlate to higher burden in this analysis. These stressors closely link to care recipient factors found to increase burden in previous studies, including: cognitive symptoms, poor functional status, and a high prevalence of behavioral disturbances (Chiao et al., 2015; Park et al., 2015; Peacock, 2013).

While this analysis included 91% of the eligible caregivers and had a large sample size, the EBP was limited to assessing only the caregivers of participants enrolled in the PACE program. The PACE program provides a variety of supportive services for their participants and, indirectly, the caregivers that may impact burden scores and distribution of burden. Therefore, the generalization of this knowledge to the larger informal caregiver community should be done cautiously. Additionally, the caregivers included in this survey were limited to one geographical area; therefore, these results may vary in different areas of the country. Lastly, this survey was administered once and does not provide insight into changes of burden throughout the care recipients' disease progression or over time enrolled in the PACE program. An interesting follow up study would be tracking burden overtime or examining the impact of PACE services on burden throughout time in the program.

Implications

The results of this gap analysis have implications for PACE program participants, informal caregivers, organization staff, the leadership team, and the entire community. The results lead to recommendations regarding program policy, development, and leadership. Additionally, the intervention design serves as a template for other PACE or community health organizations that seek to better understand and meet the needs of informal caregivers.

Impact for Program Participants, Informal Caregivers, and PACE Staff

This information can be used by staff to proactively assess and address burden in all informal caregivers while prioritizing those at the greatest risk. For staff this information serves as a guide to improve individualized, proactive informal caregiver support. For informal caregivers, being part of a PACE community that better understands their needs, burden level, and interest in services, means being more supported by the organization. When caregivers feel their needs are heard and they are more empowered by services provided by PACE, this will impact program participants indirectly by improving their quality of life, wellness, and decreasing their risks of institutionalization (Afram et al., 2014).

It is important when reviewing the demographic information of those with the greatest burden to remember that this analysis examined correlation and did not establish any relationships of causation. Because of this, and since every informal caregiver is different, it is important not to assume that those with the identified risk variables are experiencing burden. Additionally, it is important never to assume that those who do not demographically fall in the categories of greatest risk are not experiencing burden.

Each caregiver should be assessed and supported on an individual basis. However, these results can provide some guidance and serve as “warning signs” of what the IDT should be looking for in their interactions with caregivers. For example, the results indicate a moderate correlation between caregivers feeling they have limited time and a higher burden score. Therefore, if an informal caregiver reports feeling stressed about not having enough time for all their tasks, this should serve as an indicator that the caregiver could be experiencing high burden. The staff member should then utilize the *ZBI-12* to further explore the topic.

Because every informal caregiver is unique and presents differently when experiencing burden, it is important that caregiver burden is routinely and universally assessed to detect increases in burden early. Therefore, a recommendation stemming from this gap analysis is using the *ZBI-12* to assess informal caregiver burden on a standardized and regular basis. Since the PACE program already performs a comprehensive assessment of the caregiver and the program participant upon enrollment and every six months, the *ZBI-12* screening should be administered during these assessments at a minimum. The results from the screening should be discussed by the IDT during their assessment meetings and documented in the participant's chart. Since social workers are the ones who traditionally interact most with informal caregiver, it would be easiest for the assessment to be administered by them. However, any member of the IDT can execute and document the *ZBI-12* screening. This change should be reflected in organization policy to ensure that it becomes standard practice.

Impact for Leadership

Implications from *CA* results.

This gap analysis has numerous implications for leadership at the PACE regarding program development. The moderate burden level of those surveyed indicates that the organization can improve in the area of caregiver support to decrease these scores and subsequently preserve program participant independence. Results from the *CA* indicate that most of the informal caregivers served by the PACE are interested in attending educational sessions and support groups. These services are not currently provided at the PACE. Given the caregiver interest and current evidence indicating that psychoeducational sessions can mitigate burden, one recommendation stemming from this assessment is that organizational leadership consider adding an educational session, support groups, or a combination of both through psychoeducational sessions.

The leadership should consider developing a pilot psychoeducational program for caregivers. Table 2 provides some guidance regarding which caregivers are most interested. This information can be used to develop the pilot program and the recruitment of informal caregivers to attend. *CA* results indicate that most caregivers are interested in monthly sessions that occur in the morning. Lastly, caregivers at the smaller site were roughly ten percent more likely to be interested in these services than caregivers are the larger site, so if the program can only be initiated at one site, the smaller site should be the initial location.

Additionally, the survey indicates that respite care and home modifications are perceived as very helpful by informal caregivers. This serves as validation for the continued provision of these services. If organizational leadership is considering reallocating resources, these services should be bolstered or at a minimum maintained. The departments that provide these services, like home health coordinators, nursing aides, nurses, physical therapists, occupational therapists, and social workers should be expanded and/or well reimbursed for the value they bring.

Implications from *ORCA* results.

Results from the pre- and post-intervention *ORCA* suggest organizational culture at the two sites varies significantly. Results indicate staff at the smaller site perceive greater facilitation and support from organizational leadership. Additionally, the smaller site is much more likely to embrace change initiatives than the larger organization site. This is a bit surprising since resource allocation is proportional for both sites. Given the higher caregiver burden at the smaller site one may hypothesize that the team at this site is not functioning as well or that the participants at this site present more strain on the staff. However, the *ORCA* results indicate a more supported and happier team that is perceives itself as functioning well at the smaller site.

The vast difference in organizational culture and perceived support by leadership at the two sites is surprising. These results do not provide an in depth look at what may be causing these differences. Therefore, the organization leadership should use these results as a warning sign that warrants further investigation with the staff. Subsequent action or procedure changes may be necessary at the larger site to promote greater perceived staff support and facilitation.

Lastly, the lack of a significant change in the pre- and post-intervention *ORCA* results indicate that this intervention did not have an impact of organizational culture, perceived facilitation, or staff attitudes towards change initiatives. There are a few possible explanations for this lack of change. One explanation is that the *ORCAs* were administered to all members of the IDT, while this intervention primarily involved the social work staff. If the pre- and post-*ORCA* was administered solely to the social work team, significant changes may have been present. Another explanation is the low operating cost of this intervention and the project leader being a graduate student. Since the DNP student is not a permanent member of the PACE staff, does not have a leadership position within the organization, and did not have any resources at her dispense to incentives staff involvement, the extent to which she could facilitated the change and support staff through the change process was limited.

Impact for National PACEs and Practices

The design and outcomes of this gap analysis have implications for PACEs and clinical practice across the country. Other PACE programs hoping to develop caregiver services can use this EBP project as a model for how to assess and address the needs of their caregivers. The *CA* provides as a useful tool for PACEs that are creating their own caregiver assessment. The results of this gap analysis provide some insight into the burden and needs of informal caregiver of elderly with advance disease processes. However, given the limited scope of this analysis, generalization of these results should be done cautiously.

While this EBP project was completed at a PACE program, the results have implications for clinical practices everywhere. The most important implication is the prevalence and impacts of being an informal caregiver. General practitioners and those working with the geriatric population should always inquire if their patients are caregivers. If someone is serving in the caregiver role, it is important that practitioners ask about burden and common physical manifestations, like stress, insomnia, anxiety, depression, changes in eating habits, and sleep. Being a caregiver can have significant impacts of psychological, physical, social, and financial wellness. Therefore, it is the responsibility of everyone within healthcare to be inquiring about caregiving and burden. Quick, valid, and reliable tools like the *ZBI-12* should be used to assess and monitor caregiver burden overtime.

The findings in this EBP project suggest that nearly half of caregivers are interested in services, like support groups and education about caregiving. Given the wide reaching and profound consequences of unaddressed caregiver burden, it is important that healthcare professionals everywhere make supporting caregivers a priority. Caregivers should be given information about available support resources online or provided within the community and every clinic should make having an updated handout like this a priority.

Conclusion

With a rapidly aging population, chronic and debilitating disease processes that require extensive caregiving, like dementia, are on the rise in this country. Fortunately, informally caregivers provide most care to loved ones suffering from chronic, debilitating diseases. These caregivers serve as the cornerstone of long-term care in the U.S. and help maintain independence among those who would otherwise be institutionalized. Screening caregivers for burden and supporting them with evidence-based services, like psychoeducational sessions, should be made a national public health priority. This gap analysis provides insight into one caregiving population at a PACE in the Midwest. While results from this analysis should be cautiously applied to other situations, they provide a template for organizations hoping to better understand and meet the needs of the caregivers they serve. Additionally, this EBP project provides insight into which caregivers are the greatest risk for burden as well as those that may be most interested in support service.

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Appendix A

Table 1

Evaluation Table

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
Arango-Lasprilla et al., (2014). Evaluation of a group cognitive-behavioral dementia caregiver intervention in Latin America **Funding:** Authors received no financial support for the research, authorship, &/or publication of this article. **Bias:** None recognized **Country:** Colombia	Cognitive-Behavioral Model	**Design:** RCT (pre- & posttest, 3-mn follow up test) **Purpose:** Examine effectiveness of a group cognitive-behavioral intervention in improving the mental health of IC of PWD in Cali, Colombia.	**N:** 69 **n:** 39 (EG) **n**: 30 (CG) **Setting**: Small group (6-10) classroom setting in community center **Sample Demographics:** No significant differences between EG & IC. Mean age of IC: 59.4 (EG), 55.1 (CG). Female gender of IC: 87.2% (EG), 73.3% (CG). IC spouse of PwD: 17.9% (EG), 20% (CG). IC child of PwD:	**IV:** "Coping with Frustration" program **DV1:** IC life satisfaction **DV2:** IC dep. **DV3**: IC stress **DV4:** CB **"Coping with Frustration" program:** 8 weekly 2-hr sessions educating about & practicing cognitive-behavioral strategies & skills	Satisfaction with Life Scale (α=0.75), Patient-Health Questionnaire-9 item (α=0.88), Perceived Stress Scale (α=0.85), Zarit Burden Interview (α = 0.89) measured	Chi-square analysis, *t*-test, MANOVA, longitudinal multi-level model analyses	CG had generally better mental health than EG at baseline (*p*=0.002). **DV1**: b=2.47, *t*(73.95)=2.20, *p*= 0.03, no effect of time **DV2:** b= -1.82, *t*(71.97)= -2.41, *p*=0.02, no effect of time **DV3:** b= -0.85, *t*(66.42)= -0.83, *p*=0.41, no effect of time **DV4**: b= -10.93, *t*(69.43)= -	**LOE:** II **Strengths:** RCT design, placebo class offered, detailed discussion of intervention program. **Weaknesses:** No discussion of attrition rate. Sampling limited to members of the Alzheimer's Foundation in Colombia. Follow-up tests only occurred immediately & at 3 mns. Attrition not addressed. **Conclusions:** IC life satisfaction, IC dep., & CB were significantly reduced following the "Coping with Frustration" program. This effect was also observed at the 3-mn posttest. IC stress was not significantly decreased following the program & this remained true at the 3-mn posttest.

Key: AMSTAR- Assessment of Multiple Systematic Reviews measurement tool; **ANOVA**- analysis of variance; **AX** – anxiety; **CB** – caregiver burden; **CBT** – cognitive behavioral therapy; **CG**- control group; **CI** – confidence interval; **CSS** – cross-sectional study; **DCM**- Dementia care management; **Dep.-** depression; **DQ** – descriptive qualitative; **DS –** databases searched; **DV**-dependent variable; **d/t** - due to; **EG** – experimental group; **FCTP** – Family Caregiver Training Program; **GRADE** – Grades of Recommendation, Assessment, Development and Evaluation Working Group approach to evidence assessment; **hr**- hour; **I2** - ratio of true heterogeneity to total observed variation; **IC-** informal caregivers; **IV**- independent variable; **LS** – longitudinal study; **MA-** meta-analyses; **MANOVA**- multivariate analysis of variance; **MD** – mean difference; **mn**- months; **N**-number of studies (if SR) or participants in study; **n**- number of participants (if SR) or number of participants in subset; **NRCT** – Non-randomized control trials; **NRNCT** – nonrandomized noncontrolled trial; **PE** – psychoeducation; **PRISMA** – Preferred Reporting Items for Systematic Reviews and Meta-Analyses; **PSI-** psychosocial intervention**; PWD** – people with dementia; **QoL** – quality of life; **RCT** – randomized control trial; **SD –** standard deviation; **SG** – support groups; **SR-** systematic review; **T2** – between study variance; **wk**- weeks; **y.o.** – years-old; α - Cronbach's alpha value

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
			56.4% (EG), 46.7% (CG). IC mean hr.s of caring per wk: 91.9 (EG), 85.9 (CG). **Inclusion Criteria:** Related to PWD; primary IC; providing care for at least 3 mns; knowledgeable about patient's medical & family history; no self-reported history of neurological & psychiatric disorders or learning disabilities. **Attrition:** Not discussed				3.88, *p* <0.001, no effect of time	**Feasibility/Applicability to pt. population:** This study is examining the applicability of this program in Colombia. However, the magnitude of the statistically significant findings indicate that this program could be effective in numerous different cultures. This increases applicability at PACE. The program design is feasible at PACE.

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
Dickenson et al., (2017). Psychosocial	Stress-Coping Perspectives, Cognitive and	**Design:** SR of SRs & Mas	**N:** 13	**IV1:** PE	Instruments not specified. Measurements	AMSTAR	**IV1**: Moderate quality	**LOE:** I

Key: AMSTAR- Assessment of Multiple Systematic Reviews measurement tool; **ANOVA**- analysis of variance; **AX** – anxiety; **CB** – caregiver burden; **CBT** – cognitive behavioral therapy; **CG**- control group; **CI** – confidence interval; **CSS** – cross-sectional study; **DCM**- Dementia care management; **Dep.-** depression; **DQ** – descriptive qualitative; **DS –** databases searched; **DV**-dependent variable; **d/t** - due to; **EG** – experimental group; **FCTP** – Family Caregiver Training Program; **GRADE** – Grades of Recommendation, Assessment, Development and Evaluation Working Group approach to evidence assessment; **hr**- hour; **I2** - ratio of true heterogeneity to total observed variation; **IC-** informal caregivers; **IV**- independent variable; **LS** – longitudinal study; **MA-** meta-analyses; **MANOVA**- multivariate analysis of variance; **MD** – mean difference; **mn**- months; **N**-number of studies (if SR) or participants in study; **n**- number of participants (if SR) or number of participants in subset; **NRCT** – Non-randomized control trials; **NRNCT** – nonrandomized noncontrolled trial; **PE** – psychoeducation; **PRISMA** – Preferred Reporting Items for Systematic Reviews and Meta-Analyses; **PSI-** psychosocial intervention**; PWD** – people with dementia; **QoL** – quality of life; **RCT** – randomized control trial; **SD –** standard deviation; **SG** – support groups; **SR-** systematic review; **T2** – between study variance; **wk**- weeks; **y.o.** – years-old; α - Cronbach's alpha value

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews **Funding:** National Institute for Health Research **Bias:** None recognized **Country:** UK	Behavioral Theoretical Framework	**Purpose:** To review evidence from existing SRs & Mas of PSI directly targeted at IC of PWD to determine what aspects are most effective at maintaining IC health	**DS:** MEDLINE, CINAHL, EMBASE, PsychInfo, ASSIA, Scopus, Web of Science, Social Services Abstracts, Sociological Abstracts, SCIE, Cochrane, DARE **Inclusion Criteria:** SR & Mas; included statement of review; IC of PWD; interventions targeted at IC **Exclusion Criteria**: IC of other conditions; PWD institutionalized	**IV2**: Information & SG **DV1:** Dep. or AX **DV2:** QoL **DV3**: CB **PE**: Combines dementia education, skills training, and coping strategies	of AX or dep., CB, & QoL.		evidence. Mixed results. 4/7 studies found significant improvement in IC psychological well-being (CB, dep., QoL, or AX). Active IC participation and group delivery associated with better results. **IV2:** Moderate quality evidence. Mixed results. ¾ studies found significant improvement in psychological well-being (CB, dep., QoL, or AX).	**Strengths:** Thorough discussion of numerous components in programs to improve IC health outcomes. Inclusion of solely SRs increases breath of evidence examined. **Weaknesses:** No MA d/t heterogeneity of results and measurements used. **Conclusions:** Mixed results but overall evidence suggesting IC psychological well-being can be improved using psychoeducational interventions and SGs especially those actively involving Ics. **Feasibility/Applicability to pt. population:** Psychoeducational and SG interventions may be feasible at PACE. Applicability is limited by the lack of intervention details provided in study (program length, frequency of meeting, content, etc).

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DiZazzo-Miller et al., (2017). Family caregiver training program (FCTP): A randomized controlled trial **Funding:** Martha Schnebly Occupational Therapy Fund **Bias:** None recognized **Country:** U.S.A.	Inferred to be Self-Efficacy Theory	**Design:** RCT (pre- & posttest) **Purpose:** Determine if 2-hour FCTP decreases dep. & CB among IC of PWD	**N:** 36 **n:** 18 (EG) **n**: 18 (90-minute standard care presentation, CG) **Setting**: Training site in community **Sample Demographics:** IC age between 55-64 y.o.: 38.9% (EG), 55.6% (CG). Female gender of IC: 61.1% (EG), 88.9% (CG). IC spouse of PwD: 44.4% (EG), 11.1% (CG). IC child of PwD: 50% (EG), 77.8% (CG). IC Caucasian ethnicity: 72.2% (EG),	**IV:** FCTP **DV1:** CB **DV2:** IC dep. & QoL **FCTP:** 2-hr program involving PowerPoint presentation, handouts, & interactive, hands-on modules practicing ADLs	Zarit Burden Interview (α = 0.89), Beck Dep. Inventory (α =0.81), World Health QoL Measure Brief (α = 0.88)	ANOVA, paired *t*-test	No significant changes DV1 or DV2 between pre-test and 3 mn. posttest. $t(17) = 11.05$, $p = 0.30$	**LOE:** II **Strengths:** RCT that measured multiple indicators of psychological health assessed pre & 3-mn post intervention. **Weaknesses:** Although adequately powered, relatively small sample size. Minimal details provided regarding setting. Attrition not addressed. **Conclusions:** Results do not indicate improvement in CB, IC dep., or IC QoL. However, scores of CB and dep. were low prior to intervention, which could explain the lack of improvement following intervention. Further research with a larger sample size and more advanced CB is necessary to determine boarder impact of FCTP **Feasibility/Applicability to pt. population:** Feasible intervention at PACE. Could

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			38.9% (CG). **Inclusion Criteria:** IC for PWD who provide at least 4 hrs of care per week, 18 y.o. or older, fluent in English **Exclusion Criteria:** Professional or paid caregivers **Attrition:** Not discussed					be applicable to PACE but PACE IC may have more advanced CB or dep. at time of intervention so results may not be generalizable.

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Ducharme et al., (2014). Maintaining the potential of a psycho-educational program: Efficacy of a booster session after an intervention offered family caregivers at	Inferred to be Theory of Caregiver Dynamics	**Design:** RCT (pre- & posttest) **Purpose:** Evaluate if a 90-minute booster session two wks following the six-mn post-program (individual PE program entitled *Learning to*	**N:** 103 **n1:** 33 (initial class **with** booster) **n2**: 34 (initial class **without** booster) **n3**: 36 (CG) **Setting**: All within community. Most at	**IV:** PE booster **DV:** IC psychological distress **PE booster:** 90-minute individual booster session with a healthcare	Psychological Distress Index 14-item (α=0.81), Carers' Assessment of Managing Index (α=0.86)	Chi-square analyses & ANOVA for comparison of demographic information Descriptive statistics, prediction analysis (*del*	IC in booster group had fewer years of schooling than CG & group without booster (F=4.82, p=0.05) **Booster group vs. CG**: *del*	**LOE:** II **Strengths:** RCT design, relatively low attrition rate for long duration study (over 1 yr), adequately powered. **Weaknesses:** Initial sampling limited to participants diagnosed at memory clinics. No placebo for those who did not get the boost session. Details not provided regarding

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disclosure of a relative's dementia diagnosis **Funding:** Alzheimer Society of Canada **Bias:** None recognized. **Country:** Canada		*Become a Family Caregiver)* assessment further maintains or causes new positive effects after the initial intervention.	caregivers' homes. **Sample Demographics:** Only significant difference between 3 groups was that n2 had fewer yr.s of schooling (*F*=4.82, *p*=0.05). Averaged for all 3 groups. Mean age of IC: 60. Female gender of IC: 80%. **Inclusion Criteria**: Spouse or child of person with Alzheimer's disease 65 y.o. or older and diagnosed in the last 9 mns., primary caregiver **Exclusion Criteria:** IC	provider 6 mns & 2 wks after initial PE intervention. Reviewed initial content & discussed changes in IC circumstances.		statistic, *z* value)	=0.21, *z*=1.64, *p*=0.050 **Group without booster vs. CG**: *del*=0.28, *z*=2.19, *p*=0.014	setting of boosters that did not take place at home. Limited discussion of sample demographics. **Conclusions:** Results demonstrate a significantly lower amount of psychological distress when comparing those who had the *Learning to Become a Family Caregiver* program vs. the control group. However, the booster session Ics do not demonstrate any significant decrease in psychological distress when compared to those who did not have the booster session. This indicates that a booster session may not be necessary to prolong positive psychological effects following a PE intervention. **Feasibility/Applicability to pt. population:** A booster session similar to that described in the study could be feasible at PACE (performed by trained nursing staff). The applicability is limited by possible variations in initial intervention when compared to *Learning to Become a*

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			participating in SG or receiving psychotherapy at time of study **Attrition:** 13.6% (14/103, 2 from booster group, 5 from without booster group, 7 from control group)					*Family Caregiver*. Applicability is also limited by the advanced nature of dementia in most PACE participants as opposed to within 9 mns of initial diagnosis.

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Hsu et al., (2017). Sustained benefit of a psycho-educational training program for dementia caregivers in Taiwan **Funding:** Not disclosed. **Bias:** None recognized. **Country:** Taiwan	Inferred to the Chronic Care Model	**Design:** NRNCT (pre-& posttest) LS (at 3-mn, 6-mn, & 9-mn) **Purpose:** Examine the long-term effects of an intensive, short-term PE program on CB, QoL, & psychological distress among IC for PWD.	**N:** 53 **Setting**: Community facilities for those living independently **Sample Demographics:** Mean age of IC: 52.5. Female gender of IC: 85.3%. IC spouse of PwD: 29.4%. IC child of PwD: 61.8%. Mean IC yr.s of	**IV:** PE **DV1:** CB **DV2:** IC dep. **DV3:** IC QoL (mental health subset) **PE:** 4 successive weekly structured 8-hr workshops addressing (1) general information about dementia, (2)	Zarit Burden Interview (α = 0.89), General Health Questionnaire-12 (α=0.80), Short-Form Health Survey 36-item (α=0.82)	Descriptive statistics (simple means, frequencies, & 95% Cis), general estimate equations (Wald chi-squared test, standard error, & parameter estimates)	**DV1**: Wald Chi-Square 20.65, $p <$ 0.000 **DV2**: Wald Chi-Square 8.07, p =0.044 **DV3**: Wald Chi-Square 11.94, p=0.008	**LOE:** III **Strengths:** LS design allows for examination of long-term effects of intervention. **Weaknesses:** High attrition rate, small sample size, not RCT, no CG. Funding not disclosed. **Conclusions:** Moderate evidence demonstrating the long term IC benefits of intensive short PE intervention. The results should be viewed cautiously due to high attrition rate and nonrandomized sampling.

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			education: 14.2 **Inclusion Criteria:** IC of PWD at least 20 y.o., living with the PWD for at least 6 mns, PWD diagnosed by physician **Attrition:** 35.8% (19/53). Causes included death, unable to contact, & refusal of participant to be reassessed.	medical & welfare services available for PWD, (3) communication skills, environmental modifications, & strategies to manage behavior problems.				**Feasibility/Applicability to pt. population:** Four 8 hour sessions may limit the feasibility of this intervention as many IC work one or numerous jobs. Additionally, the extensive staff time requirements to lead sessions limits feasibility. Study is applicable to PACE program population but the study sample of Taiwan limits applicability.

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Kucukguclu et al., (2017). The effects of support groups on dementia caregivers: A mixed method study **Funding:** Not disclosed.	Inferred to be Theory of Caregiver Dynamics	**Design:** Mixed method design – NRNCT (pre- & post-test) & DQ (focus groups) **Purpose:** Examine the effects of SG on CB of IC of PWD.	**N:** 37 (NRNCT portion) **N:** 18 (DQ portion) **Setting**: Nursing faculty building. Quiet room with no interruptions.	**IV:** SG including education **DV1:** Overall CB **DV2:** Time dependency burden	**NRNCT:** Caregiver Burden Inventory (α = 0.92) **DQ:** Focus groups	**NRNCT:** Number & percentage distributions, two paired sample *t*-test **DQ:** Thematic content	**NRNCT**: **DV1**: *t*(29)=2.058 *p*=0.049 **DV2**: *t*(29)= -0.242 *p*= 0.810 **DV3:** *t*(29)=0.513	**LOE:** III **Strengths:** Mixed methodology allows for holistic view of impacts of SG. Provides a more accurate & full picture of experience. Appropriate analysis on the qualitative & quantitative side. Detailed outlining of intervention.

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Bias: None recognized **Country:** Turkey			**Sample Demographics:** Mean age of IC: 58.4. Female gender of IC: 100%. IC spouse of PwD: 40%. IC child of PwD: 60%. IC with college education: 40% **Inclusion Criteria:** IC of PWD who provided care for at least 4 hrs a day for at least 6 mns **Attrition:** 18.9% (7/37). Needed to participate in at least 7/10 SG meetings to be included in final analysis	**DV3**: Developmental burden **DV4**: Physical burden **DV5:** Emotional burden **DV6:** Social burden **Q1**: What have you experienced since the first day you participated in the SG meetings? **Q2**: Would you please broadly summarize the whole process of the SG meetings? **Q3**: What did you gain from these meetings?		analysis, focus group themes coded independently by two experienced qualitative researchers. Discussions to reach consensus when disagreement insured inter-rater reliability.	$p= 0.612$ **DV4**: $t(29)=0.890$ $p=0.381$ **DV5**: $t(29)=4.163$ $p<0.000$ **DV6**: $t(29)=2.854$ $p=0.008$ **DQ:** **Theme 1**: Having knowledge **Theme 2**: Calming down **Theme 3**: Acceptance	**Weaknesses:** Low level of evidence due to the NRNCT format. No CG. All of the IC who attended the SG were female. Funding not disclosed. **Conclusions:** Strong evidence that SGs decrease IC CB in the domains of emotional & social burden. DQ results indicate these benefits may be caused by SGs aiding in "having knowledge," "calming down," and "acceptance." **Feasibility/Applicability to pt. population:** The intervention described is feasible at the PACE program. All the necessary staff who contributed to the SGs already work at PACE (physicians, psychiatrists, RNs). Applicability slightly limited by this study occurring in Turkey & all the Ics being female which is not representative of the PACE program population. Additionally, 40% of Ics in this study were college educated. This is not reflective of PACE populations.

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				SG: Ten 2 hr sessions held at 2-week intervals.				

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Marim et al., (2013). Effectiveness of educational programs on reducing the burden of caregivers of elderly individuals with dementia: A systematic review **Funding:** Not disclosed. **Bias:** None recognized **Country:** Brazil	Inferred to be Theory of Caregiver Dynamics	**Design:** SR of RCTs **Purpose:** To examine the evidence on how effective education and support programs are in reducing CB in IC of PWD	**N:** 4 **n**: 403 **DS**: Medline, LILACS, Embase, Cochrane, Web of Science, SciELO, CINAHL **Inclusion criteria**: RCTs with blinded assessments, interventions which provided interdisciplinary education to IC of PWD	**IV:** interdisciplinary education & support **DV:** CB	Zarit Burden Interview (α = 0.89)	MA, MD, SD with a 95% CI, I2 & T2, sensitivity analysis	MD with 95% CI: -1.62 [-2.16,-1.08] I2: 31% T2: 22 Supporting intervention (p <0.00001)	**LOE:** I **Strengths:** Specificity of intervention and outcome measurement led to homogeneity of results. **Weaknesses:** Few studies (removed 3 outlier studies from final analysis). Details of educational intervention not provided. Funding not disclosed. **Conclusions:** After removing outliner studies, the remaining 4 articles present strong evidence supporting interdisciplinary education & support. **Feasibility/Applicability to pt. population:** Limited information regarding the types of support & education provided limits applicability as

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								well as assessment of feasibility.

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
Piersol et al., (2017). Effectiveness of interventions for caregivers of people with Alzheimer's disease and related major neurocognitive disorders: A systematic review **Funding:** Not disclosed. **Bias:** Designed & conducted by the American Occupational Therapy Association but no conflicts recognized. **Country:** U.S.A.	Inferred to be the Chronic Care Model	**Design:** SR of SRs, RCTs, NRCT, NRNCT, & CSS **Purpose:** Evaluate & synthesize current evidence for effective educational & supportive IC interventions	**N:** 43 **DS**: Medline, PsychINFO, CINAHL, Otseeker **Inclusion criteria**: Peer-reviewed scientific literature published in English, interventions within scope of occupational therapy, published from 2006-2014, study participants PWD **Exclusion Criteria:** Presentations, conference proceedings,	**IV1:** SG **IV2**: PE **DV1:** CB **DV2:** IC Dep. **PE**: Combines dementia education, skills training, and coping strategies	Zarit Burden Interview (α = 0.89), World Health QoL Measure Brief (α = 0.88), State-Trait Anxiety Inventory (α=0.91), Beck Dep. Inventory (α =0.81), Perceived Stress Scale (α=0.85), Caregiver Burden Inventory (α=0.88), Caregiver Burden Scale (α=0.91)	PRISMA, adaptation of U.S. Preventative Services Task Force rating of evidence strength	**IV1:** Two level I studies, one level II study, & one level III study indicate significant improvement in CB & IC dep. following in-person, professionally led SG. **IV2**: Six level I studies & one level III study indicate significant reduction in CB & IC dep.	**LOE:** I **Strengths:** Large sample size with 43 articles. Thorough discussion of evidence regarding different interventions for IC of PWD. **Weaknesses:** Narrative SR which is lower level of evidence than MA. Heterogeneity of studies. Funding not disclosed. **Conclusions:** Strong evidence in support of in-person, professionally led SGs & PE to reduce CB & IC dep. **Feasibility/Applicability to pt. population:** Applicable to PACE population. Feasibility of interventions are difficult to assess due to lack of information regarding SG & PE format & frequency.

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Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
			non-peer reviewed literature, dissertations, theses					

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
van't Leven et al., (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: A systematic review **Funding:** Not disclosed. **Bias:** None recognized **Country:** Netherlands	Inferred to the Chronic Care Model	**Design:** SR of RCTs **Purpose:** To provide the best current evidence about PSIs for the IC & PWD that involve face-to-face contact between professional caregivers & both the PWD & the IC	**N:** 23 **n:** 19,993 **DS**: PsychInfo, EMBASE, Medline, CINAHL, Cochrane **Inclusion Criteria:** RCT; PWD > 65 y.o. & their IC; interventions aimed at reducing mental health decline in PWD &/or IC; face-to-face interventions; English, Dutch, German, & French **Exclusion Criteria:**	**IV:** PSI **DV1:** IC mood **DV2:** IC QoL **DV3:** CB **PSI:** includes CBT, psychotherapy, family therapy, counseling, AX/dep. management, stress management, education, & SG	Zarit Burden Interview (α = 0.89), Caregiver Burden Inventory (α=0.88), Social Support Questionnaire (α=0.94), Perceived Stress Scale (α=0.85), World Health QoL Measure Brief (α = 0.88)	Cochrane rating criteria for RCTs & Oxford Centre of Evidence-based Medicine guidelines & GRADE	**Themes**: **DV1**: Moderate to strong evidence. 4/9 studies showed improvement. 3/9 showed statistically significant improvement. Programs lacking communication-skills training less effective. **DV2**: Moderate evidence. 7/10 studies found	**LOE:** I **Strengths:** Thorough discussion of different programs effect on PWD & IC CB. Forest plots for all outcomes reviewed. Use of standardized GRADE tool for evidence evaluation. **Weaknesses:** No MA d/t heterogeneity of results. Funding not disclosed. **Conclusions:** Mixed reviews but evidence suggesting improvement in IC psychological well-being following PSI. Limited information on program design. **Feasibility/Applicability to pt. population:** Discussed program similar to PACE where both PWD & IC are

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Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
			Multi-component intervention studies				significant improvement. **DV3:** Moderate evidence. 13/17 studies showed significant improvement.	addressed. Included short, long, & hospitalization programs. Hospitalization programs would not be feasible. Short to long IC PSI could be feasible. Limited discussion about what components in programs are most effective at producing outcomes. Limits applicability.

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
Zwingmann et al., (2017). Supporting family dementia caregivers: testing the efficacy of dementia care management on multifaceted caregivers' burden **Funding:** German Center of Neurodegenerative Diseases	Inferred to be the Chronic Care Model	**Design:** Retrospective secondary analysis of RCT (pre- & posttest) **Purpose:** Examine the efficacy of the DCM of IC's subjective & objective CB.	**N:** 317 **n:** 226 (DCM, EG) n: 91 (usual care, CG) **Setting:** Interventions at 5 clinic settings serving those living independently. Reassessment interviews of IC took place at participants' homes. **Sample**	**IV:** DCM **DV**: CB **DCM**: Comprehensive & interdisciplinary intervention that manages needs of PWD & IC. Focuses on three major components of care management: medication management, management	Berlin Inventory of Caregivers' Burden with Dementia Patients (α=0.85)	Descriptive statistics, paired t-tests, logistic regression analyses, Bonferri corrected *p*-values	**Objective CB**: Emotional support EG vs. CG (OR=0.81, *SE*=0.45, CI_{95}=[-0.008, 1.70], *p*=0.075, d_{ppc2}= -2.527, d_{corr}=-2.436) **Subjective CB d/t behavior change:** CB d/t cognition of PWD EG	**LOE:** II **Strengths:** Large sample size, RCT design. **Weaknesses:** Exclusion of PWD who had visual or hearing impairments (common in elderly). Discrepancy in EG vs. CG size. EG & CG only reassessed once at 12 mns. Attrition not addressed. **Conclusions:** Significant difference between EG & CG in 6 of 20 CB areas assessed in favor of DCM decreasing CB. The remaining 14 areas assess showed no significant

Key: AMSTAR- Assessment of Multiple Systematic Reviews measurement tool; **ANOVA**- analysis of variance; **AX** – anxiety; **CB** – caregiver burden; **CBT** – cognitive behavioral therapy; **CG**- control group; **CI** – confidence interval; **CSS** – cross-sectional study; **DCM**- Dementia care management; **Dep.-** depression; **DQ** – descriptive qualitative; **DS –** databases searched; **DV**-dependent variable; **d/t** - due to; **EG** – experimental group; **FCTP** – Family Caregiver Training Program; **GRADE** – Grades of Recommendation, Assessment, Development and Evaluation Working Group approach to evidence assessment; **hr**- hour; **I2** - ratio of true heterogeneity to total observed variation; **IC-** informal caregivers; **IV**- independent variable; **LS** – longitudinal study; **MA-** meta-analyses; **MANOVA**- multivariate analysis of variance; **MD** – mean difference; **mn**- months; **N**-number of studies (if SR) or participants in study; **n**- number of participants (if SR) or number of participants in subset; **NRCT** – Non-randomized control trials; **NRNCT** – nonrandomized noncontrolled trial; **PE** – psychoeducation; **PRISMA** – Preferred Reporting Items for Systematic Reviews and Meta-Analyses; **PSI-** psychosocial intervention**; PWD** – people with dementia; **QoL** – quality of life; **RCT** – randomized control trial; **SD –** standard deviation; **SG** – support groups; **SR-** systematic review; **T2** – between study variance; **wk**- weeks; **y.o.** – years-old; α - Cronbach's alpha value

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
Bias: None recognized. **Country:** Germany			**Demographics:** Not significant differences between EG & CG. Mean age of IC: 64.6 (EG), 62.6 (CG). Female gender of IC: 73% (EG), 70.3% (CG). IC spouse of PwD: 46% (EG), 45% (CG). IC child of PwD: 39.8% (EG), 38.5% (CG). Mean IC hr.s of caring per mn: 141.2 (EG), 185.2 (CG). **Inclusion criteria:** PWD at least 70 y.o. & living at home, have & provide information about IC. **Attrition:** Not discussed.	of treatment & care, & IC support & education. Program duration was 12 mns.			vs. CG (OR=0.70, SE=0.41, CI$_{95}$=[-0.12, 1.51], p=0.093, d_{ppc2}= -3.666, d_{corr}=-3.202), CB d/t aggression & resistance of PWD EG vs. CG (OR=0.80, SE=0.38, CI$_{95}$=-[0.03, 1.55], p=0.038, d_{ppc2}= -3.324, d_{corr}=-2.988), CB d/t depression of PWD EG vs. CG (OR=0.72, SE=0.40, CI$_{95}$=[-0.007, 1.50], p=0.072, d_{ppc2}= -2.176, d_{corr}=-2.086), CB d/t late symptoms of PWD EG vs.	differences between the CG & EG at the 12 mn. reassessment. **Feasibility/Applicability to pt. population:** Program described is similar to PACE with interdisciplinary interventions. Aspects of medication management & care management are already being addressed in PACE. Addressing IC education & support could be beneficial at PACE. Incorporating aspects of IC social integration, mental health & financial affairs is more feasible than managing IC physical health. Applicability limited by little information provided regarding modules that comprised interventions.

Key: AMSTAR- Assessment of Multiple Systematic Reviews measurement tool; **ANOVA**- analysis of variance; **AX** – anxiety; **CB** – caregiver burden; **CBT** – cognitive behavioral therapy; **CG**- control group; **CI** – confidence interval; **CSS** – cross-sectional study; **DCM**- Dementia care management; **Dep.-** depression; **DQ** – descriptive qualitative; **DS –** databases searched; **DV**-dependent variable; **d/t** - due to; **EG** – experimental group; **FCTP** – Family Caregiver Training Program; **GRADE** – Grades of Recommendation, Assessment, Development and Evaluation Working Group approach to evidence assessment; **hr**- hour; **I2** - ratio of true heterogeneity to total observed variation; **IC-** informal caregivers; **IV**- independent variable; **LS** – longitudinal study; **MA-** meta-analyses; **MANOVA**- multivariate analysis of variance; **MD** – mean difference; **mn**- months; **N**-number of studies (if SR) or participants in study; **n**- number of participants (if SR) or number of participants in subset; **NRCT** – Non-randomized control trials; **NRNCT** – nonrandomized noncontrolled trial; **PE** – psychoeducation; **PRISMA** – Preferred Reporting Items for Systematic Reviews and Meta-Analyses; **PSI-** psychosocial intervention**; PWD** – people with dementia; **QoL** – quality of life; **RCT** – randomized control trial; **SD –** standard deviation; **SG** – support groups; **SR-** systematic review; **T2** – between study variance; **wk**- weeks; **y.o.** – years-old; α - Cronbach’s alpha value

Citation	Conceptual Framework	Design/Method	Sample/Setting	Major Variables & Definitions	Measurement	Analysis	Findings	Decision for Use
							CG (OR=1.51, *SE*=0.51, CI$_{95}$=[0.51, 2.51], *p*=0.003, d_{ppc2}= -4.766, d_{corr}=-2.781) **Subjective CB d/t perceived conflicts between needs & responsibilities to care**: CB d/t financial loss (OR=0.97, *SE*=0.50, CI$_{95}$= [-0.01,1.95], *p*=0.051, d_{ppc2}= -0.312, d_{corr}=-0.663)	

Key: AMSTAR- Assessment of Multiple Systematic Reviews measurement tool; **ANOVA**- analysis of variance; **AX** – anxiety; **CB** – caregiver burden; **CBT** – cognitive behavioral therapy; **CG**- control group; **CI** – confidence interval; **CSS** – cross-sectional study; **DCM**- Dementia care management; **Dep.-** depression; **DQ** – descriptive qualitative; **DS –** databases searched; **DV**-dependent variable; **d/t** - due to; **EG** – experimental group; **FCTP** – Family Caregiver Training Program; **GRADE** – Grades of Recommendation, Assessment, Development and Evaluation Working Group approach to evidence assessment; **hr**- hour; **I2** - ratio of true heterogeneity to total observed variation; **IC-** informal caregivers; **IV**- independent variable; **LS** – longitudinal study; **MA-** meta-analyses; **MANOVA**- multivariate analysis of variance; **MD** – mean difference; **mn**- months; **N**-number of studies (if SR) or participants in study; **n**- number of participants (if SR) or number of participants in subset; **NRCT** – Non-randomized control trials; **NRNCT** – nonrandomized noncontrolled trial; **PE** – psychoeducation; **PRISMA** – Preferred Reporting Items for Systematic Reviews and Meta-Analyses; **PSI-** psychosocial intervention**; PWD** – people with dementia; **QoL** – quality of life; **RCT** – randomized control trial; **SD –** standard deviation; **SG** – support groups; **SR-** systematic review; **T2** – between study variance; **wk**- weeks; **y.o.** – years-old; α - Cronbach's alpha value

Appendix B

Table 2

Synthesis Table

Author	Arango-Lasprilla	Dickenson	DiZazzo-Miller	Ducharme	Hsu	Kucukguclu	Marim	Piersol	van't Leven	Zwingmann
Year	2014	2017	2017	2014	2017	2017	2013	2017	2013	2017
Design/Level of Evidence:	RCT/II	SR/I	RCT/II	RCT/II	NRNCT LS/III	MMS(NRNCT + DQ) /III	SR/I	SR/I	SR/I	RCT/I
Study Characteristics										
Demographics										
Age (Mean y.o.)	59.4		55-64	60	52.5	58.4				64.6
Female (%)	87.2		61.1	80	85.3	100				73
Spouse of PwD (%)	17.9		44.4	n/p	29.4	40				46
Child of PwD (%)	56.4		50	n/p	61.8	60				39.8
Setting:										
Community Dwelling	X	X	X	X	X	X	X	X	X	X
Sample Size/ # of Studies Included	69	13 studies	36	103	53	37 (NRNCT), 18 (DQ)	4	43	23	317
Measurement Tools	PHQ-9, PSS, SLS, ZBI	Unspecified – AX, Dep., & QoL	BDI, WHOQOL-BREF, ZBI	CAMI	GHQ, SF-36, ZBI	CBI	ZBI	BDI, CBI, CBS, PSS, STAI,	CBI, PHQ-9, PSS, SSQ,	BIZA-D, CBS, CAMI

Key: AX- anxiety; **BDI -** Beck's Depression Inventory; **BIZA-D –** Berlin Inventory of Caregivers' Burden with Dementia Patients**; CAMI –** Carers' Assessment of Managing Index**; CBI –** Caregiver Burden Inventory**; CBS -** Caregiver Burden Scale**; CBT-** cognitive behavioral therapy; **CG** - control group**; d/t –** due to; **Dep. –** depression; **DQ** – descriptive qualitative**; DV-** dependent variables; **EG** – experimental group; **GHQ-12** – General Health Questionnaire – 12; **hrs**- hours; **IC** – informal caregiver; **IV-** independent variables; **LS** – longitudinal study**; MMS –** mixed method study**; mn. –** months; **n/p –** not provided; **NRNCT** – nonrandomized noncontrolled trial; **PDI** – Psychological Distress Index; **PHQ-9** - Patient Health Questionnaire -9; **PSS** – Percieved Stress Scale; **PwD** – person with dementia; **QoL** – quality of life; **RCT** – randomized control trial; **SF-36** – Short Form Health Survey – 36; **SLS** – Satisfaction with Life Scale; **SR -** systematic review; **SSQ** – Social Support Questionnaire; **WHOQOL-BREF** – World Health Quality of Life Measure Brief; **w/o** – without; **y.o.** – years old; **ZBI –** Zarit Burden Interview; **#** - number; * - statistically significant with *p*-value ≤ 0.050; ⍰ - increased; ⍰ - decreased; **≠** - not statistically significant; **+ -** strong level of evidence in SR**; ~ -** moderate level of evidence in SR

								WHOQOL-BREF, ZBI	WHOQOL-BREF, ZBI	
Duration of Intervention (hrs)	16		2	1.5	32	20				12 mn.
IV – Interventions										
CBT	X								X	
Education Booster Course				X						
Interdisciplinary Management							X		X	X
Skills Training	X	X	X							
Structured Education	X	X	X		X	X	X	X	X	X
Support Groups		X				X		X	X	
DV										
Anxiety		↓~				↓				
Caregiver Burden	↓*	↓~	≠		↓*	↓(* for overall, social, & emotional CB)	↓*	↓+	↓~	↓(* in CB d/t late symptoms, aggression & resistance of PwD)
Depression	↓*	↓~	≠		↓*			↓+		
Life Satisfaction	↑*									
Mood										↑+
Psychological Distress				Compared to EG w/o booster ≠, Compared to CG ↓*						

Key: AX- anxiety; **BDI -** Beck's Depression Inventory; **BIZA-D –** Berlin Inventory of Caregivers' Burden with Dementia Patients**; CAMI –** Carers' Assessment of Managing Index**; CBI –** Caregiver Burden Inventory**; CBS -** Caregiver Burden Scale**; CBT-** cognitive behavioral therapy; **CG** - control group**; d/t –** due to; **Dep. –** depression; **DQ** – descriptive qualitative**; DV-** dependent variables; **EG** – experimental group; **GHQ-12** – General Health Questionnaire – 12; **hrs**- hours; **IC** – informal caregiver; **IV-** independent variables; **LS** – longitudinal study**; MMS –** mixed method study**; mn. –** months; **n/p –** not provided; **NRNCT** – nonrandomized noncontrolled trial; **PDI** – Psychological Distress Index; **PHQ-9** - Patient Health Questionnaire -9; **PSS** – Percieved Stress Scale; **PwD** – person with dementia; **QoL** – quality of life; **RCT** – randomized control trial; **SF-36** – Short Form Health Survey – 36; **SLS** – Satisfaction with Life Scale; **SR -** systematic review; **SSQ** – Social Support Questionnaire; **WHOQOL-BREF** – World Health Quality of Life Measure Brief; **w/o** – without; **y.o.** – years old; **ZBI** – Zarit Burden Interview; # - number; * - statistically significant with *p*-value ≤ 0.050; ↑ - increased; ↓ - decreased; ≠ - not statistically significant; + **-** strong level of evidence in SR**;** ~ **-** moderate level of evidence in SR

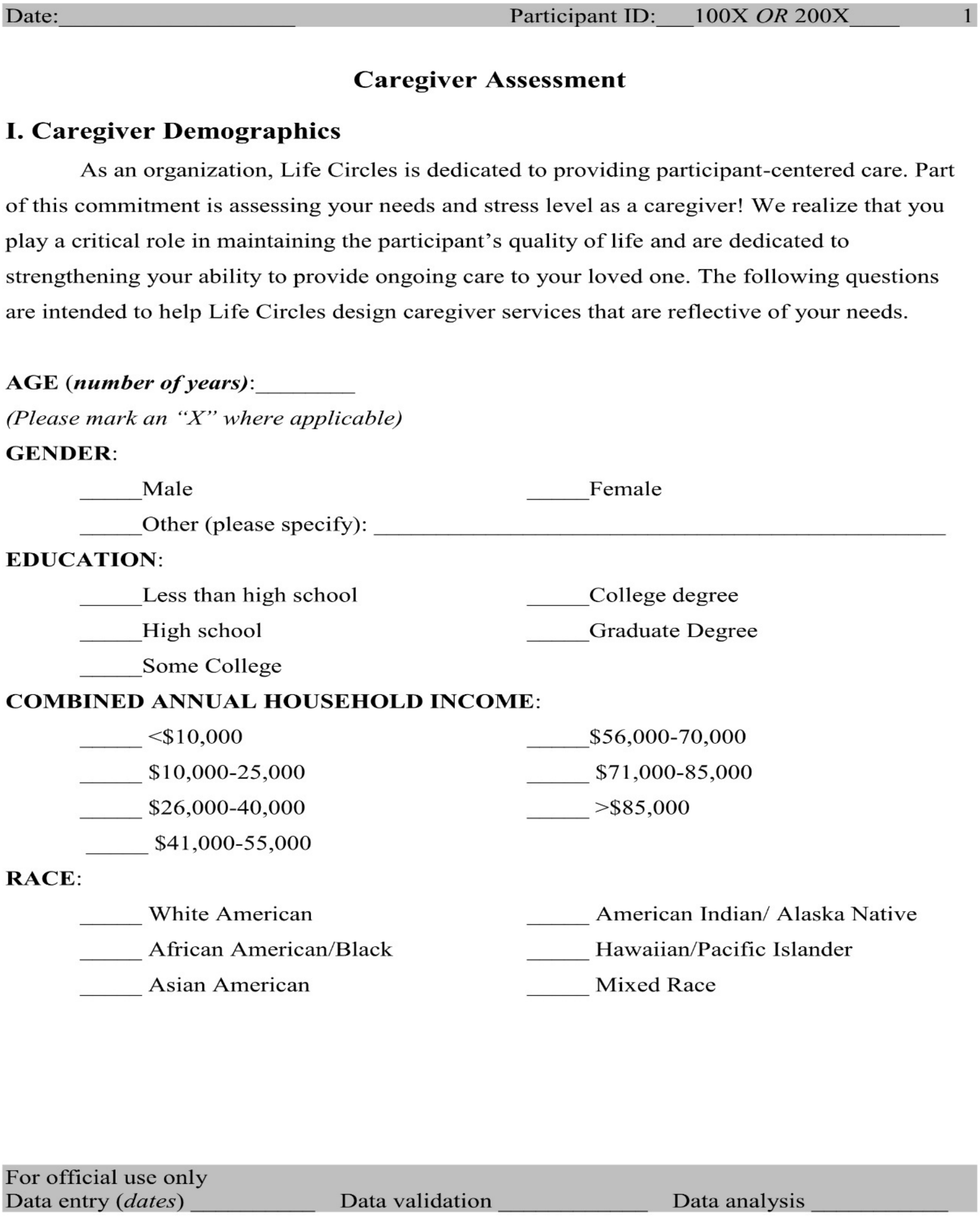
QoL		↑~	≠		↑*				↑~	
Stress	≠									

Key: AX- anxiety; **BDI -** Beck's Depression Inventory; **BIZA-D –** Berlin Inventory of Caregivers' Burden with Dementia Patients**; CAMI –** Carers' Assessment of Managing Index**; CBI –** Caregiver Burden Inventory**; CBS -** Caregiver Burden Scale**; CBT-** cognitive behavioral therapy; **CG** - control group**; d/t –** due to; **Dep. –** depression; **DQ** – descriptive qualitative**; DV-** dependent variables; **EG** – experimental group; **GHQ-12** – General Health Questionnaire – 12; **hrs**- hours; **IC** – informal caregiver; **IV-** independent variables; **LS** – longitudinal study**; MMS –** mixed method study**; mn. –** months; **n/p –** not provided; **NRNCT** – nonrandomized noncontrolled trial; **PDI** – Psychological Distress Index; **PHQ-9** - Patient Health Questionnaire -9; **PSS** – Percieved Stress Scale; **PwD** – person with dementia; **QoL** – quality of life; **RCT** – randomized control trial; **SF-36** – Short Form Health Survey – 36; **SLS** – Satisfaction with Life Scale; **SR -** systematic review; **SSQ** – Social Support Questionnaire; **WHOQOL-BREF** – World Health Quality of Life Measure Brief; **w/o** – without; **y.o.** – years old; **ZBI –** Zarit Burden Interview; # - number; * - statistically significant with *p*-value ≤ 0.050; ↑ - increased; ↓ - decreased; ≠ - not statistically significant; + **-** strong level of evidence in SR**;** ~ **-** moderate level of evidence in SR

Appendix C

Figure 1

Caregiver Assessment (CA)



Date:___________________ Participant ID:___100X *OR* 200X____ 1

Caregiver Assessment

I. Caregiver Demographics

As an organization, Life Circles is dedicated to providing participant-centered care. Part of this commitment is assessing your needs and stress level as a caregiver! We realize that you play a critical role in maintaining the participant's quality of life and are dedicated to strengthening your ability to provide ongoing care to your loved one. The following questions are intended to help Life Circles design caregiver services that are reflective of your needs.

AGE (***number of years)***:________

(Please mark an "X" where applicable)

GENDER:

_____Male
_____Other (please specify): ____
_____Female

EDUCATION:

_____Less than high school
_____High school
_____Some College
_____College degree
_____Graduate Degree

COMBINED ANNUAL HOUSEHOLD INCOME:

_____ <$10,000
_____ $10,000-25,000
_____ $26,000-40,000
_____ $41,000-55,000
_____$56,000-70,000
_____ $71,000-85,000
_____ >$85,000

RACE:

_____ White American
_____ African American/Black
_____ Asian American
_____ American Indian/ Alaska Native
_____ Hawaiian/Pacific Islander
_____ Mixed Race

For official use only
Data entry (*dates*) ___________ Data validation _____________ Data analysis ____________

Date:___________________ Participant ID:___100X *OR* 200X____ 2

I. Caregiver Demographics

(Please mark an "X" where applicable)

RELATION TO PACE PARTICIPANT:

_____ Spouse
_____ Child
_____ Sibling
_____ Grandchild
_____ Friend
_____ Niece/Nephew
_____ Other (please specify): ____

HOURS OF CARE PROVIDED PER WEEK:

_____ <5 Hours
_____ 16-20 Hours
_____ >30 Hours
_____ 5-10 Hours
_____ 21-25 Hours
_____ 11-15 Hours
_____ 26-30 Hours

YEARS OF CAREGIVING (***number of years)***: _______

PRIMARY MEDICAL CONDITION OF PARTICIPANT:

_____ Dementia
_____ Parkinson's Disease
_____ Congestive Heart Failure
_____ Kidney Failure
_____ Chronic Obstructive Pulmonary Disease (COPD)
_____ Stroke
_____Other (please specify):____

DURATION OF PRIMARY DIAGNOSIS (***number of years)***: ________

What aspect of disease management is most challenging to you as a caregiver?

____

____

____

____

____

Date:___________________ Participant ID:___100X *OR* 200X____ 3

I. Caregiver Demographics

(Please mark an "X" where applicable)

What challenges of caregiving contribute most to your caregiver stress?

_____Aggressive behavior

_____ Mobility assistance

_____ Financial stress

_____ Managing own grief

_____Wandering behavior

_____ Incontinence/Toileting care

_____Time commitment

_____Lack of sleep

_____Daily activities assistance (showering, dressing, meals, etc.)

Would the institutionalization or death of your loved one result in housing/financial insecurity?

_____Yes _____No

Are you currently working outside of the house?

_____No

_____ Yes, part-time

_____ Yes, full-time

_____ Yes, intermittently

If yes, what shift do you work?

_____ 1st _____ 2nd _____ 3rd

Do you have other dependents?

_____Yes _____No

Which Life Circles location does your loved one attend?

_____Muskegon _____Holland

Date:___________________ Participant ID:___100X *OR* 200X____ 4

II. Zarit Burden Interview 12-Item

For the each question please place in "X" in the box indicating that you "never" (0), "rarely" (1), "sometimes" (2), "quite frequently" (3), or "nearly always" (4) experience the below.

Date:___________________ Participant ID:___100X *OR* 200X____ 5

III. Caregiver Interest in Services

Our organization is dedicated to strengthening your ability to provide ongoing care to your loved one in order to maintain home placement. Understanding you will help us design caregiver services that are reflective of your needs. Please answer the following questions to help Life Circles better understand your needs.

1.) **Which caregiver resources would be most helpful to you:** ***(****Please mark an "X" in front of the two most helpful****)***
_____Individual, in person caregiver education & skills training
_____Group, in person caregiver education & skills training
_____Respite care (in addition to scheduled day center attendance)
_____Support groups _____Online resources
_____Printed resources _____Video resources
_____Home environmental modification

(Please mark an "X" where applicable)

2.) **How interested would you be in attending in person educational sessions regarding caregiver coping strategies, challenges, and skills for those assisting loved ones at home?**
_____Not at all interested _____Somewhat interested _____Very interested

3.) **If these educational sessions were offered, how frequently would you attend?**
_____Weekly _____Every third month
_____Monthly _____Annually

4.) **How interested would you be in attending a caregiver support group offered at Life Circles?**
_____ Not at all interested _____ Somewhat interested _____ Very interested

5.) **If these support groups were offered, how frequently would you attend?**
_____Weekly _____Every third month
_____Monthly _____Annually

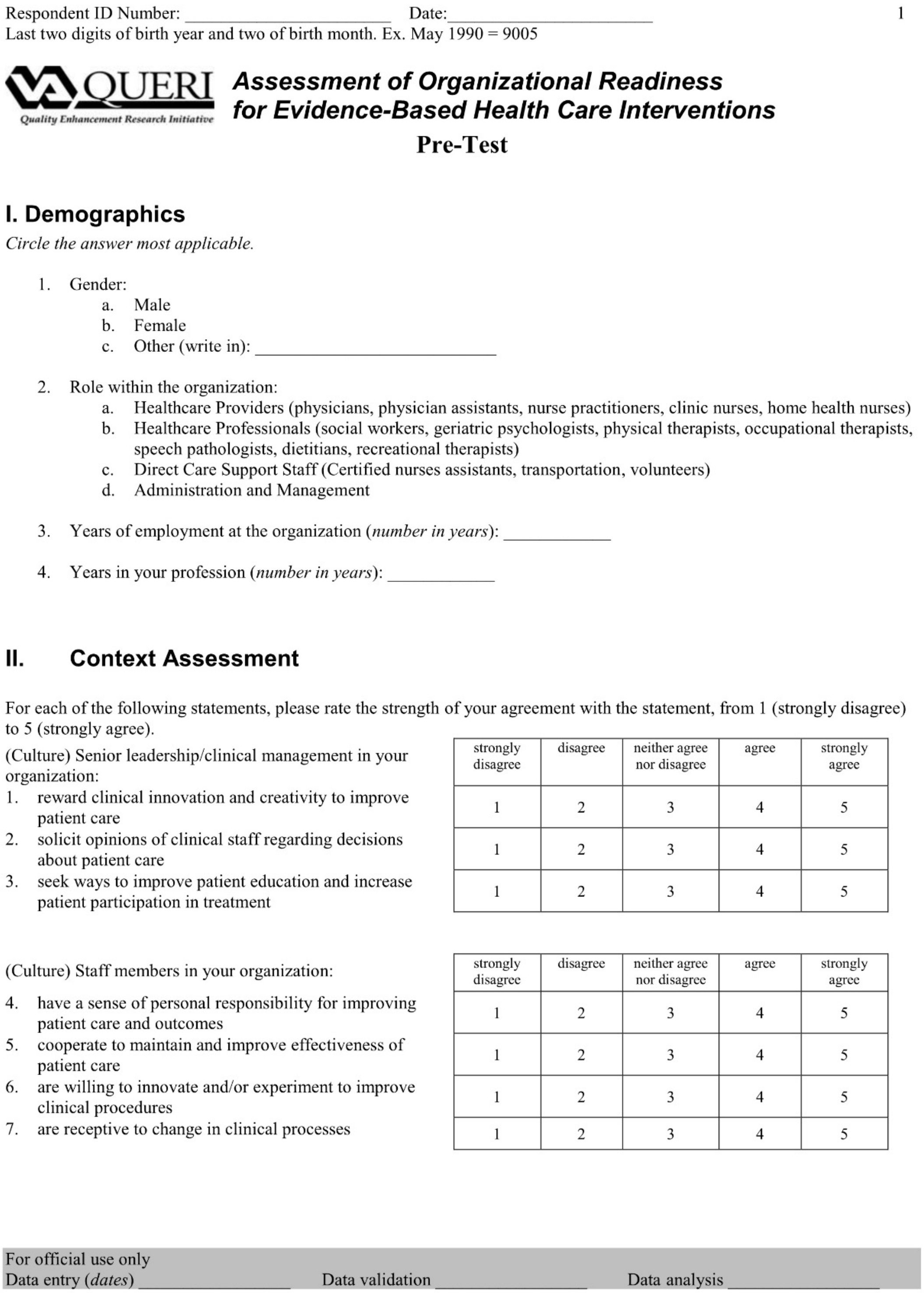
6.) **If support groups and/or educational sessions were offered at Life Circles, what time of day would work best for you to attend?**
_____Morning (9AM-11AM) _____Late Afternoon (3PM-5PM)
_____Early Afternoon (noon-2PM) _____Evening (6PM-8PM)

Thank you for completing the caregiver assessment survey! By doing so you have helped Life Circles and PACEs across the country better meet your needs and the needs of other caregivers like you.

Appendix D

Figure 2

Organizational Readiness for Change Assessment (ORCA)



Respondent ID Number: ________________________ Date:________________________ 1

Last two digits of birth year and two of birth month. Ex. May 1990 = 9005

QUERI
Quality Enhancement Research Initiative

Assessment of Organizational Readiness for Evidence-Based Health Care Interventions

Pre-Test

I. Demographics

Circle the answer most applicable.

1. Gender:
   a. Male
   b. Female
   c. Other (write in): ___________________________

2. Role within the organization:
   a. Healthcare Providers (physicians, physician assistants, nurse practitioners, clinic nurses, home health nurses)
   b. Healthcare Professionals (social workers, geriatric psychologists, physical therapists, occupational therapists, speech pathologists, dietitians, recreational therapists)
   c. Direct Care Support Staff (Certified nurses assistants, transportation, volunteers)
   d. Administration and Management

3. Years of employment at the organization (*number in years*): ____________

4. Years in your profession (*number in years*): ____________

II. Context Assessment

For each of the following statements, please rate the strength of your agreement with the statement, from 1 (strongly disagree) to 5 (strongly agree).

(Culture) Senior leadership/clinical management in your organization:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
1. reward clinical innovation and creativity to improve patient care	1	2	3	4	5
2. solicit opinions of clinical staff regarding decisions about patient care	1	2	3	4	5
3. seek ways to improve patient education and increase patient participation in treatment	1	2	3	4	5

(Culture) Staff members in your organization:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
4. have a sense of personal responsibility for improving patient care and outcomes	1	2	3	4	5
5. cooperate to maintain and improve effectiveness of patient care	1	2	3	4	5
6. are willing to innovate and/or experiment to improve clinical procedures	1	2	3	4	5
7. are receptive to change in clinical processes	1	2	3	4	5

For official use only

Data entry (*dates*) _________________ Data validation _________________ Data analysis _________________

Date: _________________ Respondent ID Number: _______________________ 2

II. Context Assessment

For each of the following statements, please rate the strength of your agreement with the statement, from 1 (strongly disagree) to 5 (strongly agree).

(Leadership) Senior leadership/Clinical management in your organization:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
8. provide effective management for continuous improvement of patient care	1	2	3	4	5
9. clearly define areas of responsibility and authority for clinical managers and staff	1	2	3	4	5
10. promote team building to solve clinical care problems	1	2	3	4	5
11. promote communication among clinical services and units	1	2	3	4	5

(Measurement) Senior Leadership/clinical management in your organization:	strongly disagree	disagree	Neither agree nor disagree	agree	strongly agree
12. provide staff with information on Life Circles performance measures and guidelines	1	2	3	4	5
13. establish clear goals for patient care processes and outcomes	1	2	3	4	5
14. provide staff members with feedback/data on effects of clinical decisions	1	2	3	4	5
15. hold staff members accountable for achieving results	1	2	3	4	5

(Readiness for change) Opinion leaders in your organization:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
16. believe that the current practice patterns can be improved	1	2	3	4	5
17. encourage and support changes in practice patterns to improve patient care	1	2	3	4	5
18. are willing to try new clinical protocols	1	2	3	4	5
19. work cooperatively with senior leadership/clinical management to make appropriate changes	1	2	3	4	5

(Resources) In general in my organization, when there is agreement that change needs to happen:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
20. we have the necessary support in terms of budget or financial resources	1	2	3	4	5
21. we have the necessary support in terms of training	1	2	3	4	5
22. we have the necessary support in terms of facilities	1	2	3	4	5
23. we have the necessary support in terms of staffing	1	2	3	4	5

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III. Facilitation Assessment:

For each of the following statements, please rate the strength of your agreement with the statement, from 1 (strongly disagree) to 5 (strongly agree):

(Characteristics) Senior leadership/clinical management will:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
1. propose a project that is appropriate and feasible	1	2	3	4	5
2. provide clear goals for improvement in patient care	1	2	3	4	5
3. establish a project schedule and deliverables	1	2	3	4	5
4. designate a clinical champion(s) for the project	1	2	3	4	5

(Characteristics) The Project Clinical Champion:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
5. accepts responsibility for the success of this project	1	2	3	4	5
6. has the authority to carry out the implementation	1	2	3	4	5
7. is considered a clinical opinion leader	1	2	3	4	5
8. works well with the intervention team and providers	1	2	3	4	5

(Role) Senior Leadership/Clinical management/staff opinion leaders:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
9. agree on the goals for this intervention	1	2	3	4	5
10. will be informed and involved in the intervention	1	2	3	4	5
11. agree on adequate resources to accomplish the intervention	1	2	3	4	5
12. set a high priority on the success of the intervention	1	2	3	4	5

(Role) The implementation team members:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
13. share responsibility for the success of this project	1	2	3	4	5
14. have clearly defined roles and responsibilities	1	2	3	4	5
15. have release time or can accomplish intervention tasks within their regular work load	1	2	3	4	5
16. have staff support and other resources required for the project	1	2	3	4	5

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III. Facilitation Assessment:

For each of the following statements, please rate the strength of your agreement with the statement, from 1 (strongly disagree) to 5 (strongly agree):

(Style) The implementation plan for this intervention:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
17. identifies specific roles and responsibilities	1	2	3	4	5
18. clearly describes tasks and timelines	1	2	3	4	5
19. includes appropriate provider/patient education	1	2	3	4	5
20. acknowledges staff input and opinions	1	2	3	4	5

(Style) Communication will be maintained through:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
21. regular project meetings with the project champion and team members	1	2	3	4	5
22. involvement of quality management staff in project planning and implementation	1	2	3	4	5
23. regular feedback to clinical management on progress of project activities and resource needs	1	2	3	4	5
24. regular feedback to clinicians on effects of practice changes on patient care/outcomes	1	2	3	4	5

(Style) Progress of the project will be measured by:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
25. collecting feedback from patients regarding proposed/implemented changes	1	2	3	4	5
26. collecting feedback from staff regarding proposed/implemented changes	1	2	3	4	5
27. developing and distributing regular performance measures to clinical staff	1	2	3	4	5
28. providing a forum for presentation/discussion of results and implications for continued improvements	1	2	3	4	5

(Resources) The following are available to make the selected plan work:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
29. staff incentives	1	2	3	4	5
30. equipment and materials	1	2	3	4	5
31. patient awareness/need	1	2	3	4	5
32. provider buy-in	1	2	3	4	5
33. intervention team	1	2	3	4	5
34. evaluation protocol	1	2	3	4	5

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III. Facilitation Assessment:

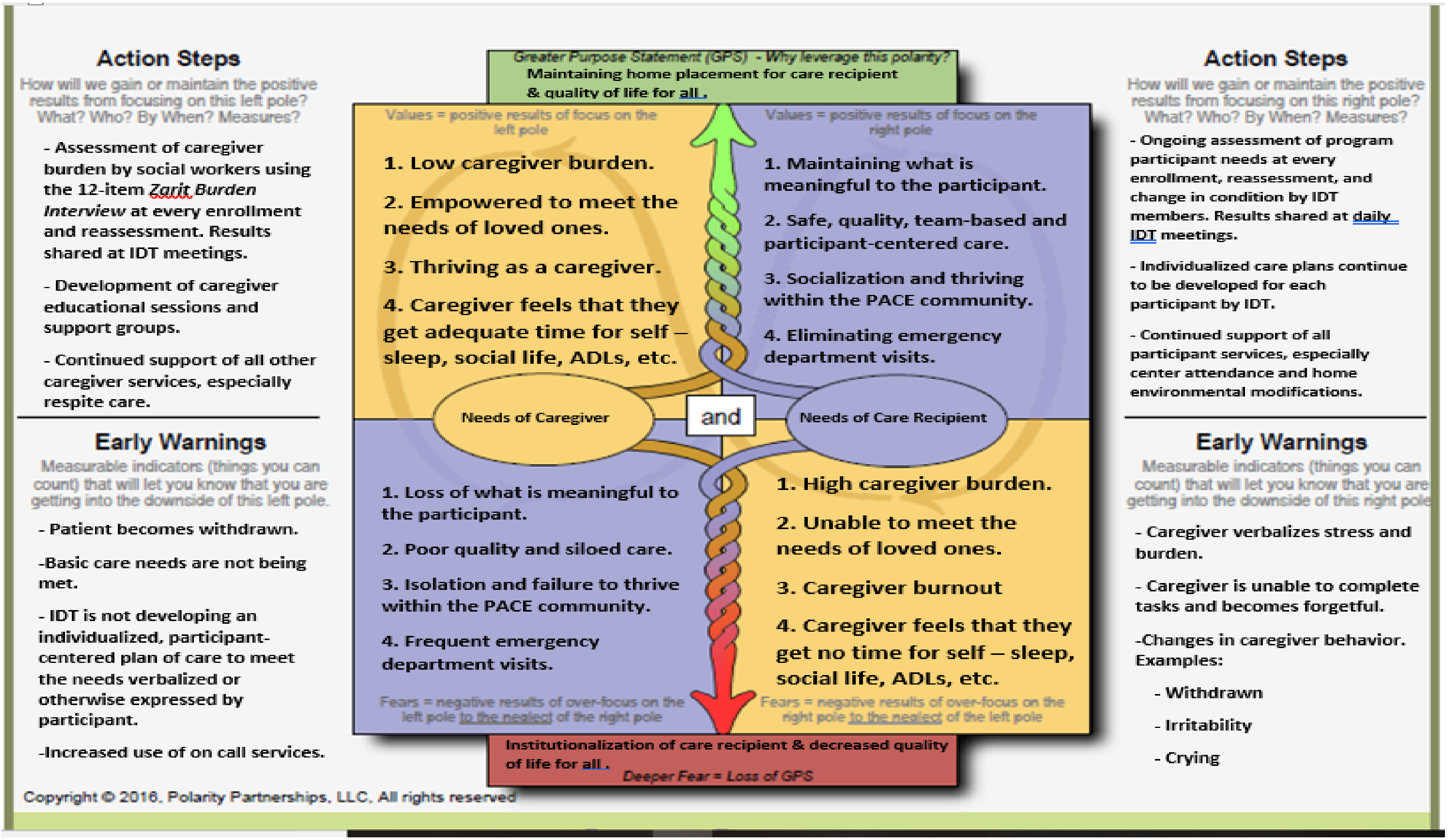
For each of the following statements, please rate the strength of your agreement with the statement, from 1 (strongly disagree) to 5 (strongly agree):

(Evaluation) Plans for evaluation and improvement of this intervention include:	strongly disagree	disagree	neither agree nor disagree	agree	strongly agree
35. periodic outcome measurement	1	2	3	4	5
36. staff participation/satisfaction survey	1	2	3	4	5
37. patient satisfaction survey	1	2	3	4	5
38. dissemination plan for performance measures	1	2	3	4	5
39. review of results by clinical leadership	1	2	3	4	5

Appendix E

Figure 3

Needs of Caregiver and Needs of Care Recipient - Polarity Map



Greater Purpose Statement (GPS) - Why leverage this polarity?

Maintaining home placement for care recipient & quality of life for all.

Action Steps

How will we gain or maintain the positive results from focusing on this left pole? What? Who? By When? Measures?

- Assessment of caregiver burden by social workers using the 12-item *Zarit Burden Interview* at every enrollment and reassessment. Results shared at IDT meetings.
- Development of caregiver educational sessions and support groups.
- Continued support of all other caregiver services, especially respite care.

Values = positive results of focus on the left pole

1. Low caregiver burden.
2. Empowered to meet the needs of loved ones.
3. Thriving as a caregiver.
4. Caregiver feels that they get adequate time for self – sleep, social life, ADLs, etc.

Values = positive results of focus on the right pole

1. Maintaining what is meaningful to the participant.
2. Safe, quality, team-based and participant-centered care.
3. Socialization and thriving within the PACE community.
4. Eliminating emergency department visits.

Action Steps

How will we gain or maintain the positive results from focusing on this right pole? What? Who? By When? Measures?

- Ongoing assessment of program participant needs at every enrollment, reassessment, and change in condition by IDT members. Results shared at daily IDT meetings.
- Individualized care plans continue to be developed for each participant by IDT.
- Continued support of all participant services, especially center attendance and home environmental modifications.

Needs of Caregiver

and

Needs of Care Recipient

Early Warnings

Measurable indicators (things you can count) that will let you know that you are getting into the downside of this left pole.

- Patient becomes withdrawn.
- Basic care needs are not being met.
- IDT is not developing an individualized, participant-centered plan of care to meet the needs verbalized or otherwise expressed by participant.
- Increased use of on call services.

1. Loss of what is meaningful to the participant.
2. Poor quality and siloed care.
3. Isolation and failure to thrive within the PACE community.
4. Frequent emergency department visits.

Fears = negative results of over-focus on the left pole to the neglect of the right pole

1. High caregiver burden.
2. Unable to meet the needs of loved ones.
3. Caregiver burnout
4. Caregiver feels that they get no time for self – sleep, social life, ADLs, etc.

Fears = negative results of over-focus on the right pole to the neglect of the left pole

Early Warnings

Measurable indicators (things you can count) that will let you know that you are getting into the downside of this right pole

- Caregiver verbalizes stress and burden.
- Caregiver is unable to complete tasks and becomes forgetful.
- Changes in caregiver behavior. Examples:
  - Withdrawn
  - Irritability
  - Crying

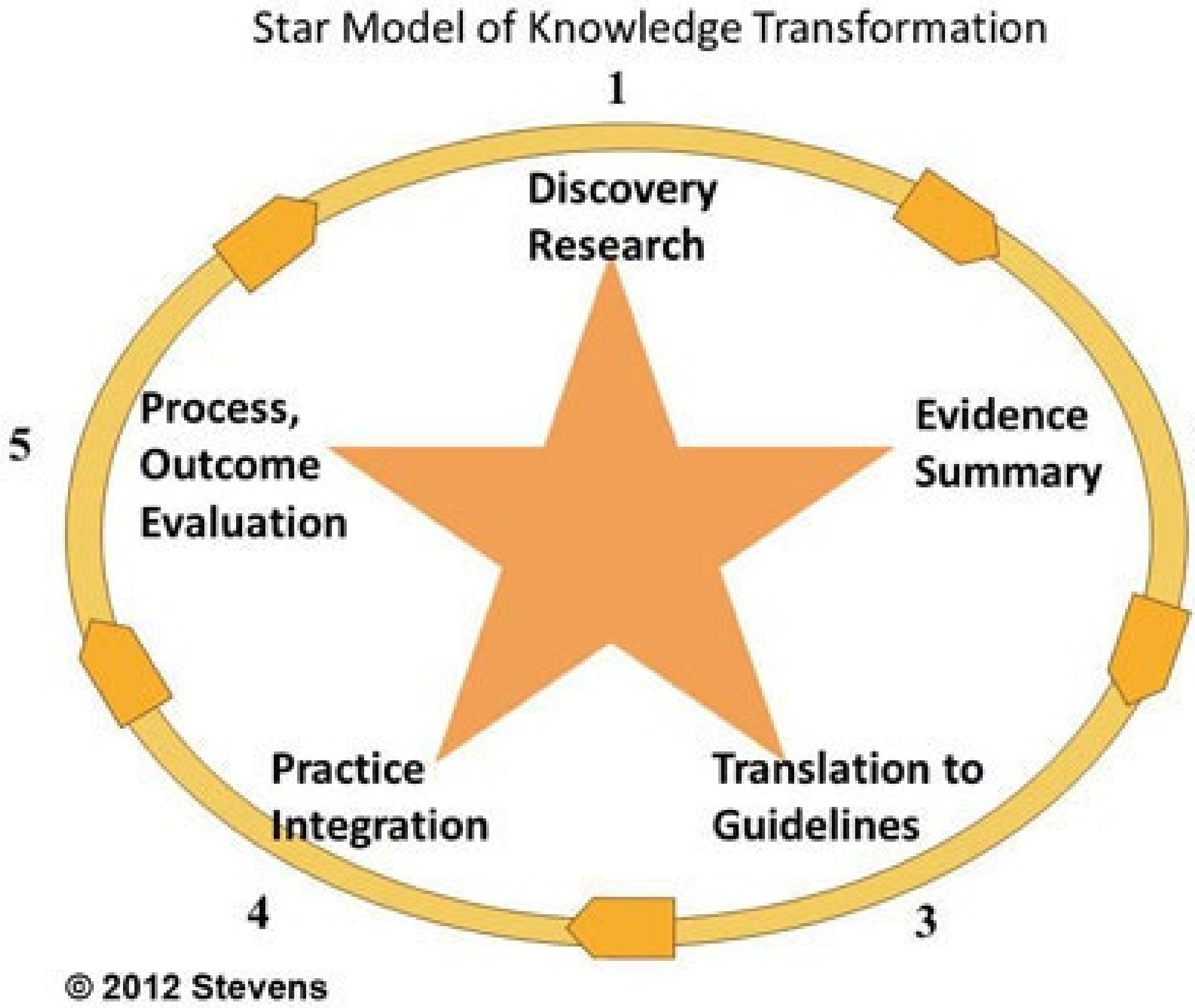
Institutionalization of care recipient & decreased quality of life for all.

Deeper Fear = Loss of GPS

Appendix F

Figure 4

The Star Model of Transformation



Appendix G

Table 3

Key CA Outcomes

Demographic Group Most Likely to Display Key Outcomes			
	High Burden (*ZBI-12* ≥ 17)	Interest in Educational Sessions	Interest in Support Groups
ZBI-12 Score	NA	High burden (N=38): 28 (73.7%)	High burden (N=38): 26 (68.4%)
Gender	Female (N=103): 31 (30.1%)	Female (N=103): 61 (59.2%)	Female (N=103): 60 (58.3%)
Age	Middle age (40-64 yrs.) (N=74): 19 (25.7%)	Middle age (N=74): 44 (59.5%)	Middle age (N=74): 43 (58.1%)
Employment	Working (N=67): 18 (26.9%)	Working (N=67): 38 (56.7%)	Working (N=67): 36 (53.7%)
Dependents	Yes (N=52): 15 (28.8%)	Yes (N=52): 30 (57.7%)	Yes (N=52): 30 (57.7%)
Race	Mixed race (N=13): 5 (38.5%)	Mixed race (N=13): 9 (69.2%)	Mixed race (N=13): 8 (61.5%)
Education	College degree (N=45): 11 (24.4%)	College degree (N=45): 29 (64.4%)	College degree (N=45): 24 (53.3%)
Income	$56K-85K (N=15): 6 (40%)	$56K-85K (N=15): 10 (66.7%)	$56K-85K (N=15): 9 (60%)
Relation to Care Recipient	Spouses (N=34): 10 (29.4%) Children (N=77): 20 (26%)	Siblings (N=22): 14 (63.6%) Spouses (N=34): 19 (55.9%)	Spouses (N=34): 21 (61.8%) Children (N=77): 40 (51.9%)
Primary Diagnosis of Care Recipient	CHF (N=7): 3 (42.9%) Type II DM (N=8): 3 (37.5%) Dementia (N=63): 18 (28.6%)	Renal failure (N=10): 8 (80%) Type II DM (N=8): 6 (75%) Dementia (N=63): 38 (60.4%)	Type II DM (N=8): 6 (75%) Renal failure (N=10): 7 (70%) Parkinson’s Dz (N=5): 3 (60%)
Primary Stressor	ADL assistance (N=38) & limited time (N=38): 30 & 30 (78.9%)	Lack of sleep (N=46): 33 (71.7%)	Lack of sleep (N=46): 32 (69.6%)