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Early stage memory loss interventions: utilization, impact and the experience of living alone.

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Abstract

Early stage memory loss interventions: utilization, impact and the experience of living alone.

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Alzheimer's disease and related dementias (ADRD) are an increasing public health concern. Currently, over 5 million Americans are living with Alzheimer's disease. Receiving a diagnosis of ADRD is life altering and changes the anticipated trajectory of one's life. Currently, there is no medical treatment that can delay or stop the progression of these diseases. Increasingly, research has focused on psychosocial education and support group interventions for individuals in the early stages of ADRD. These interventions offer individuals an opportunity to learn about their diagnosis and find peer-based support. These groups represent a promising intervention that can help individuals adapt to the diagnosis. This dissertation comprises three distinct manuscripts that focus the current state of research in early stage psychosocial support and offer new knowledge about the characteristics of people who participate in these programs.

Psychosocial support for individuals with early stage memory loss; a critical review of the literature, is the first manuscript. This paper reports the findings from a systematic review of the scientific literature on early stage memory loss interventions. Ten studies were included after a three step process of evaluation. The content of the interventions was similar in scope; most investigations included a weekly module of education alone with a professionally facilitated peer-based support group discussion. Results showed that across studies sample sizes were

generally small, ranging in size from 24-330. The studies occurred in both urban and suburban environments. However participant samples had limited heterogeneity amongst participants. The vast majority of the participants identified as being Caucasian. Three important gaps were identified in this review: limited person centered programming, racial and socioeconomic disparities in utilization, and the exclusion of individuals who live alone without a care partner to accompany them to a program. The need for evidence based psychosocial supports will continue to grow as more individuals are diagnosed with ADRD. These interventions need to be inclusive and adaptive to the diversity of populations impacted by an ADRD diagnosis.

As the demand and utilization of early stage interventions grows, additional focus on the measured outcomes of these interventions is warranted. Manuscript two, The impact of an outcome: moving towards meaningful measurement in early stage dementia interventions, is a systematic review that examines the current focus of outcome measurement in early stage interventions. Eight studies met inclusion criteria and were abstracted to identify and evaluate participant outcome measures. This manuscript discusses characteristics of the measures, identifies participant and systems level characteristics that make selecting outcome measures in early-stage ADRD challenging, and provides recommendations about future directions of outcomes measurement.

The third manuscript, Living alone with dementia: the effect of self-efficacy, mood, and quality of on the concept of well-being, presents the results from an examination of baseline data collected from 144 individuals with early stage ADRD who participated in a randomized control trail of a psychosocial early stage support group. The aim of this investigation was to determine

if there were differences in overall well-being (assessed by self-reported measures of self-efficacy, mood, and quality of life) among persons living alone versus those living with a partner. A multivariate analysis of variance was executed on the two groups. Results indicated that there were no significance differences in the groups on the three outcome measures. Analysis of demographic data showed that those who lived alone were older and more likely to be female. This study contributes valuable knowledge about the individuals who seek psychosocial support services and illuminates gaps which can be addressed through additional research.

In sum, these three studies examine issues that are critical to elevating and expanding the scope of psychosocial intervention research in early stage ADRD. They contribute a unique perspective and new information to expand our understanding of the interventions and the unique role for nursing science researchers in the realm of psychosocial research.

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I am especially appreciative of my chair, Rebecca Logsdon who provided hours upon hours of commitment to my scholarly growth during my program. She is a true mentor and I will be forever grateful.

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DEDICATION

To my husband Al Souza who has been a source of unwavering support, endless encouragement and love. I could never have completed this journey without you. To my three little ones Katrin, Mila and Alice you all are my source of joy.

Chapter 1

Psychosocial support for individuals with early stage memory loss: a critical review of the literature.

Abstract

There is an increasing focus on the development and implementation of psychosocial educational and support interventions for individuals in the early stages of memory loss. A systematic and critical review of the literature was undertaken to examine who is currently utilizing psychosocial early stage dementia interventions. Ten studies met inclusion for review. Lack of engagement with persons with dementia in the design and implementation of programs, racial and socioeconomic disparities, and unknown needs of individuals living alone were identified as critical gaps that create barriers to widespread utilization of support and education programs for people in the early stages of dementia. Opportunities exist for nurse science researchers to increase diverse patient participation. This includes expanding the focus on access and integration of psychosocial services as a part of comprehensive care for persons diagnosed with a dementia disorder.

Keywords
Alzheimer's, ADRD, Dementia, early stage, education, interventions, psychosocial care

Background

The ageing of the baby-boomer cohort has contributed to the increased the number of individuals who, by age alone, are identified as being at risk of developing Alzheimer's disease or a Related Dementia (ADRD). Currently 5.4 million Americans are living with Alzheimer's disease, and that number is expected to increase to 13.2 million by 2050, if no preventive or curative interventions are identified (Alzheimer's Association, 2015). The increasing impact of ADRD on both the quality of life of older adults and the health care system has created an urgency to understand and identify the earliest biological mechanisms of the disease. This has resulted in research initiatives and public health policies that target early screening and diagnosis for memory loss impairment among older adults. For example, in the United States it is recommended protocol that Medicare beneficiaries receive a cognitive screen as part of their annual wellness exam (Cordell et al., 2013). This health policy aims to identify early changes in memory that might be indicative of memory loss disorder (Cordell et al., 2013). Affirmation of a memory loss disorder resulting from a primary care memory screen is just the tip of the iceberg for affected individuals. Dementia diagnosis and subsequent care management is complex and long in duration. Attending to the biological and physiological manifestations of the disease represent one component of comprehensive dementia care. Education and support needs of persons with dementia represent a critical psychosocial component of post-diagnostic care.

In the scientific quest to identify and understand the physical causes and impact of ADRD, health care professionals cannot neglect that this disease creates uncertainty and disrupts the planned trajectory of the diagnosed individual's life. Mitigating the fear, uncertainty, and anxiety that come from this diagnosis is critical to helping people live well despite the diagnosis.

It is important to address these concerns early, through utilization of evidence based psychosocial interventions that are tailored for those with an early memory loss diagnosis. Nurses and other health professionals that work closely with newly diagnosed individuals are uniquely positioned to educate, engage and facilitate access to psychosocial supports. Cancer care provides a model for the integration of psychosocial care. In 2004, the Institute of Medicine (IOM) published "*The psychosocial needs of women with breast cancer".* The IOM report showed that the common unmet psychosocial needs for women with breast cancer were: lack of information, knowledge, and skills to manage the disease (Hewitt, Herdman, & Holland, 2004). They found that the cumulative impact of these gaps leads to poor coping and increased emotional problems. Individuals with dementia experience similar challenges and unmet psychosocial care needs. Ultimately, the culmination of their unmet needs can lead to increased stigma and compound the impact of the disease. For some, the unresolved psychosocial needs create additional psychological co-morbidities such as depression and anxiety (Hewitt et al., 2004). The suggested recommendations from the IOM report are relevant and transferable to individuals with memory loss. Critically pertinent are the recommendations that call for implementation of pathways of care that are holistic and integrate both biomedical and psychosocial needs. Such an approach can help individuals increase their wellbeing despite a serious and life altering diagnosis. Although educate and support mechanisms have been developed to address the psychosocial needs of individuals with dementia, gaps exist in the widespread dissemination and integration of these programs. This lack of utilization coupled with fragmented dementia care pathways from point of diagnosis to post-diagnostic support prevent this critical component of dementia care from reaching those in need (Spector & Orrell, 2010).

The aims of this investigation were to: a.) comprehensively review the published scientific literature to identify who is currently utilizing education and support programs; b.) elucidate gaps that currently exist and act as potential barriers to widespread utilization of these programs; and c.) identify research opportunities to decrease these barriers and increase the utilization of psychosocial care for individuals in the early stages of dementia.

Methods

A systematic search of the scientific literature was performed in May 2016 to identify psychosocial interventions focused on post-diagnostic education and support for persons with early stage ADRD. Support was broadly defined, and included individual counseling or group based support. PubMed, PsycInfo, CINAHL and Google Scholar databases were used to access relevant articles from diverse interdisciplinary perspectives of nursing, medicine, psychology and social work. The keywords used to identify articles were: early-stage dementia support, interventions and dementia, Alzheimer's and patient resources, post diagnostic support and dementia, and psychosocial interventions and early memory loss. To be included, studies needed to be published within the past 16 years, from 2000-2016, and written in English. While care partners were often a part of the programming, studies were excluded if they focused primarily on the psychosocial needs of the care partners. Investigations that did not provide objective measures of participant outcomes were also excluded from this review. Studies that had less than 20 total participants were also excluded from review.

The review process included three interrelated steps (Figure 1.1): (1) titles and abstracts were screened for inclusion and exclusion criteria; (2) studies included following this screening were subjected to a full-text screening by two reviewers; (3) the final set of studies that met the parameters for inclusion in the review were abstracted using a standardized reporting form.

Results

The literature search yielded 1965 publications that were screened, with 18 reviewed in full. Studies that were excluded after full-article review are referenced in Table 1.1, and Table 1.2 provides the sample characteristics of the ten studies that met criteria and were selected for inclusion.

Study Designs

Five investigations (Laakkonen et al., 2016; Logsdon et al., 2010; Marshall et al., 2014; Quinn et al., 2016; and Waldorff et al., 2012) were randomized controlled trials; two investigations were non-randomized trials with a comparison condition (Buettner & Fitzsimmons, 2009; Joosten-Weyn Banningh et al., 2010), and three investigations were single group pre-post trials (Brodaty and Low, 2004; Roberts and Silverio, 2009; and Gaugler et al., 2011).

Sample Populations

Recruitment sources for programs came from two primary sources: memory clinics and locally based Alzheimer's Associations. Across all studies the sample sizes were generally small, ranging from 24 to 330 with a mean of 59.8 participants. Study locations and reported population demographics indicated that primary utilization of these programs was by individuals who lived in urban or suburban locations within close proximity to the programs. There was minimal heterogeneity of race and ethnicity across the participant sample, the vast majority identified as Caucasian. Studies recruited individuals with early stage dementia, most commonly defined by the Mini Mental Status Exam (Folstein, & McHugh, 1975). Joosten-Weyn Banningh et al. (2011) targeted the very earliest population of memory loss, those diagnosed with Mild

Cognitive Impairment. Across all studies, MMSE scores ranged from a mean low of 23.4 to a mean high of 25.8.

Program Content

Program content across all studies was similar in scope. Table 1.3, details intervention content as described by the authors. Studies typically included a weekly module of education along with a professionally facilitated peer-based support group discussion. The total duration of programs ranged from 4 to 12 weeks, and most sessions were 90 to 120 minutes. Four studies evaluated programs that were developed and delivered by Alzheimer's Association Chapters (Brodaty & Low, 2004; Gaugler et al., 2011; Logsdon et al., 2010; Roberts, 2009); while six developed their own programs (Fitzsimmons, 2009; Joosten-Weyn Banningh et al., 2011; Laakkonen et al., 2016; Marshall et al., 2014; Quinn et al., 2014; Waldorff et al., 2012). Programs varied in the extent and nature of care partner involvement. All but one study (Fitzsimmons, 2009) included care partners in the program. Two programs (Brodaty and Low (2004) and Waldorff et al (2012)) included a component that was individually tailored to the participants. Participants in the "Making Memories" program by Brodaty and Low (2004) had one individualized counseling session. In the study by Waldorff et al. (2012), individuals with memory loss and their care partners had individual sessions with a counselor at the beginning and end of the program with an additional optional counseling session where participants could have a facilitated meeting with their network of close family and friends.

Outcome Measures

All studies measured to varying degrees the impact of the interventions on psychosocial wellbeing of the individual with memory loss. The most frequent measures included quality of life, self-efficacy and measures of mood, commonly assessed though depression measures.

When care partners were involved in the interventions, they often were asked to respond to measures as a proxy for the person with dementia. The studies' measurement periods ranged from immediately post intervention to six months post intervention. Measures of cost effectiveness and health care utilization were collected in four of the more recent studies (Laakkonen et al., 2012; Marshall et al., 2014; Quinn et al., 2014; Waldorff et al., 2012).

Discussion

The purpose of this review was to identify characteristics of individuals who are currently utilizing early stage interventions, and to compare the content across early stage interventions. To respond to the growing need for education and support that will arise from larger numbers of diagnosed individuals; researchers, clinicians and those providing psychosocial education and support programs need to understand who is utilizing these programs and examine the characteristics of individuals who may be unrepresented in current offerings. This will help improve the relevance, reach, and impact of psychosocial supports and address gaps and barriers that exist in the development and implementation of these programs. Critical examination of barriers and gaps can inform the development of programs that meet the diversity of needs of individuals who are living with a memory loss disorder. Three important gaps were identified in the programs included in this review: limited person-centered programming, racial and socioeconomic disparities in utilization, and the exclusion of individuals living alone with dementia without a care partner to accompany them to the program.

Meeting the emerging needs of the person with dementia with person-centered programming

A substantial gap in psychosocial care for persons with memory loss exists because their voices have largely been absent from the development of psychosocial interventions, though this is changing as community organizations and academic institutions reach out to those who are diagnosed to assist in the development and design of psychosocial supports (Quinn et al., 2014; Wiersma et al., 2016). Acceptance and adaptation to memory loss is a non-linear process that is complicated by a multitude of personal, environmental and societal factors (Laakkonen et al., 2016). Health professionals see the early stages of the disease as a unique window of opportunity for diagnosed individuals to engage in planning for their future care needs. Health providers are acutely aware of what the disease takes from individuals as it progresses and what it demands of those who provide support. For the diagnosed individuals there is a personal adaptation to the disease that may have a very a different intensity and trajectory, and newly diagnosed individuals also operate from a different knowledge base (Hellstrom & Torres, 2014). They navigate a challenging space between maintaining their current capabilities and preparing for and awaiting progressive cognitive decline (Derksen, Vernooij-Dassen, Gillissen, Olde Rikkert, & Scheltens, 2006; Manthorpe, 2014; L Robinson, Clare, & Evans, 2005). As health care providers' understanding of biomedical indicators of memory loss continues to increase our ability to diagnose individuals earlier in the disease process, it becomes critical that we recognize and attend to the psychosocial care needs that develop as a result of diagnostic confirmation.

Psychosocial interventions such as support groups, counseling and education can help individuals cope with their diagnosis by providing individuals with the education, support and

community pathways to support their current and future needs. However, to deliver psychosocial supports that are relevant and helpful we need to understand the diversity of needs and perspectives that represent the heterogeneity of the diagnosed population. Interventions developed without the influence and perspective of the individuals with memory loss risk missing the mark. This person-centered perspective will help to insure that we are moving towards evidence based interventions that are responsive and effective, and that fully involve individuals in the development, implementation, and evaluation of early stage services.

Racial and Socioeconomic Diversity

A second substantial gap made visible by this review is the lack of participation from individuals with diverse racial and socioeconomic backgrounds. Unfortunately, as this review shows, even the best research on early stage programs is characterized by modest sample sizes comprising mostly White, well-educated individuals with demographic profiles that indicate higher socioeconomic status. Even in the studies that were done in diverse urban settings there was little if any participation from diverse racial and ethnic communities (Goldsilver & Gruneir, 2001; Roberts, 2009). Thus, none of the samples in the review were reflective of the epidemiologic presence of ADRD for communities of color and individuals who are living at or near the poverty line (Alzheimer's Association, 2015; Chin, 2012; Zuckerman et al., 2013).

Racial and economic health disparities have been shown to disproportionately impact the care individuals with dementia receive. In Zuckerman et al.'s (2008) study of Medicare beneficiaries, minorities had less access to dementia specialists, and cultural and environmental factors contributed to low utilization of dementia care services. This is a serious gap that needs

to be addressed by researchers and those offering community-based programs, with the influence and input of representatives from these communities. Further research is needed to help widen the array of access points though which individuals receive psychosocial support. Utilizing research methodologies that are inclusive of community engagement in research will help develop programs that are tailored to meet the heterogeneous representation of ADRD in our communities.

Living alone

Researchers, community organizations, and the medical community at large recognize the important role of care partners. The majority of studies represented in this review included components that were geared towards partnered individuals, especially spousal care partners. However, many individuals do not have this network of family and friends to provide support. In a special report by the Alzheimer's Association it was estimated that there are over 800,000 American's living alone with Alzheimer's disease (Alzheimer's Association, 2012). There is paucity of research aimed at understanding the needs and experience of individuals who are living alone with dementia. Without further research directed specifically at this population we can only hypothesize the impact that living alone would have on the psychosocial health needs of individuals with dementia. It would be reasonable to expect that persons with memory loss who live alone also experience a need for psychosocial interventions, and that their needs may differ from those who have care partners (Eichler et al., 2016). The focus of program content would need to be augmented to incorporate the specific needs of these individuals. For example, for the person living alone there might be a greater reliance on external care networks, yet accessing and navigating these networks will be more different for the person who does not have an identified

care partner. Addressing these knowledge gaps and creating psychosocial interventions that are tailored to meet these needs would be quite impactful for the growing population who do not have a spousal or familial care partners.

Implications for practice and research

The need for psychosocial supports will continue to grow as more individuals in our aging population are diagnosed with memory loss disorders. As evidenced in this review, large gaps exist in the development and utilization of these programs. These gaps can be mitigated by including individuals with dementia in the planning and evaluation of programs. Preliminary efforts are underway to address this need (Dupuis, Gillies, Carson, & Whyte, 2011; Moore & Hollett, 2003; Pesonen, Remes, & Isola, 2011) Moreover, emphasis needs to be taken by nurse researchers and social service providers to address barriers that restrict access to community based programs that have thus far limited the utilization of these psychosocial supports to a small and homogeneous group. The lack of diverse demographic profiles in both academic studies and program evaluations leaves a number of unanswered questions. What program components are most valuable to persons newly diagnosed? Are we missing the target that is most important to individuals with memory loss? How can providers best meet the needs of individuals who are members of underserved social, racial, or ethnic groups, or who live alone? These queries present opportunities for nursing science researchers to examine, dismantle, and restructure the pathways to psychosocial health for all individuals diagnosed with a memory loss disorder. While psychosocial care represents a "non-medical" component of care, it makes a significant contribution to overall health (Hewitt et al., 2004). Psychosocial care needs to be integrated into the medical care model that permeates primary care. It should not remain a superfluous addition that is only targeted at a narrow population of individuals. Nurses are in a unique position to

lead the expansion and integration of psychosocial care beyond our current limited reach (Louise Robinson et al., 2011). Clinically, nurses are a trusted resource that increases patient comfort in disclosing concerns but also increases diverse socioeconomic access to medical care (Minstrell et al., 2015; Williams & Jones, 2006) Nurse led approaches to patient care which incorporate psychosocial domains such as health promotion and health education offer a patient centered approach that is needed to address the growing population of individuals that will be diagnosed with ADRD.

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Chapter 2

The impact of an outcome: moving towards meaningful outcomes measurement in early stage dementia interventions.

Abstract

Psychosocial and Psychoeducational groups are increasingly utilized to provide support and education to individuals who have been diagnosed with a memory loss disorder. Attaining research outcomes from the person with memory loss who attends these groups can present measurement challenges. This review examines current interventions and discusses the challenges that exist for researchers seeking meaningful measurement outcomes. A systematic review of the literature was completed which identified psychosocial interventions measuring outcomes for the persons with dementia. Eight studies met inclusion criteria. Participant and systems level factors contribute to measurement challenges. Increased collaboration amongst researchers and inclusion of individuals with dementia in the design, implementation, and selection of measured outcomes would further inform this critical and growing area of research.

Keywords**:** dementia, early stage memory loss, interventions, outcome measurement.

Introduction

Providing support and education for persons diagnosed with Alzheimer's disease or related disorders (ADRD) is a focus of non-pharmacological intervention research, propelled by recent policy efforts aimed at increasing early identification and timely and appropriate post-diagnostic support for diagnosed individuals and families (Fargo et al., 2014; World Health Organization, 2012). Receiving a diagnosis of ADRD is life altering. It is progressive condition for which there is currently no cure and no disease altering pharmacological interventions (Bossen, Pringle Specht, & Mckenzie, 2009; Mountain & Craig, 2012). The ability to detect early and even prodromal stages of ADRD has increased the challenge to identify and meet the education and support needs of those living in the community with memory loss, including coping, planning, and living well with their diagnosis (Burgener, Buettner, Beattie, & Rose, 2009). Education and support group programs are a promising approach to meeting these needs. Psychosocial education and support groups for persons with early stage ADRD are intended to help individuals cope with their diagnosis and make important decisions regarding support and future plans during the early stages of memory loss. Educational groups use a model based on more formal education and interaction, while social support groups are based on a model of support and sharing among peers who are adjusting to similar experiences. Hybrid programs include components of both education and support.

As these newly developed group interventions are implemented in both clinical (e.g. memory clinics) and community-based (e.g. Alzheimer's Association) settings, health care providers and researchers face unique challenges in evaluating their acceptability and efficacy for the persons they serve. For example, early stage ADRD is characterized by varying degrees

of cognitive and functional impairment. Some participants in early stage groups may be able to accurately describe their current activities, and others may have difficulty remembering day to day events. Thus, self-report measures that rely on memory of specific events may not be appropriate for evaluating these groups. Another challenge is that meaningful outcomes in research are often defined as significant changes from baseline that are attributed to the intervention. However, the progressive nature of ADRD complicates the measurement of these changes, since delaying decline (rather than improvement) may represent a successful outcome. Because of these unique characteristics, meaningful measurement for those with progressive memory loss typical of ADRD is less concrete, more individualized. While early stage interventions are widely recommended and appear promising, a critical mass of empirical evidence to support their efficacy has not yet developed. Study samples of current investigations are small and the outcome measurements are variable. If early stage interventions are indeed beneficial to those with early memory loss, measurable evidence of their efficacy is essential. It is also critical to maximize knowledge gained in these studies by collaborating to develop a common focus amongst researchers in this area.

The aims of this investigation were to elucidate the current measurement foci of psychosocial education and support programs for people who are newly diagnosed with ADRD by: a) evaluating the current focus of outcome measurement in these programs in the scientific literature; b) discussing participant- and systems-level characteristics that make selecting outcome measures challenging; and c) developing recommendations about future directions of outcome measurement for early stage memory loss educational and support programs.

Methods

A systematic search of online literature was conducted in May, 2016, using online databases of PubMed, CINAHL, PsycINFO and Google Scholar. The following keywords were used to locate intervention studies: early-stage dementia support, interventions and dementia, Alzheimer's and patient resources, post diagnostic support and dementia, and psychosocial interventions and early memory loss. Psychosocial interventions are a growing area of focus for many diverse disciplines such as social work, rehabilitation science, nursing, medicine, sociology, and psychology. For this reason, articles were not excluded by discipline. Three interrelated steps (figure 2.1) were taken to insure a systematic review: (1) titles and abstract were screened based on inclusion and exclusion criteria; (2) studies that were included following this initial screening receive a full-text screening by two reviewers; (3) the final selected set of studies selected for inclusion were abstracted using a standard reporting form.

Selection criteria

Inclusion was limited to studies that were published from 2000-2016, and written in English. Investigations were included if they had a psychosocial and/or psychoeducational group format. Psychoeducational groups were defined as those that presented didactic information about the diagnosis, disease process, and information on coping and adapting to memory loss. Psychosocial programs were defined as groups that provided information, coping strategies, and support for group members based on a model of participant support and information sharing.

Cognitive rehabilitation and training programs were excluded from this review, as their primary focus is on memory preservation rather than psychosocial well-being, and they have been recently reviewed elsewhere (Bahar-Fuchs, Clare, & Woods, 2013). Investigations that did

not collect objective outcome data from persons with memory loss, such as program evaluations, protocol descriptions, and pilot investigations and those with fewer than 10 participants were also excluded from this review.

Results

The initial literature search yielded 336 publications that were identified across search engines (PubMed, CINAHL, PsycINFO and Google Scholar). Eighteen articles that met eligibility screening were retrieved for a full text review. Ten articles were excluded after a full review (Table 2.2). The characteristics of the eight studies that met inclusion criteria after full text review and data extraction are included in Table 2.1.

Participant Characteristics

Each of the interventions included in this review were reportedly designed specifically for older adults with early stage memory loss due to ADRD. Participants in these studies ranged in age from a mean low of 63 years (Gaugler et al., 2011) to a mean high of 81 years old (Fitzsimmons, 2009).

All studies included in this review used the Mini-Mental State Exam (MMSE) as a baseline cognitive measure (Folstein, Folstein, & McHugh, 1975). The MMSE measures cognitive impairment on a range of 0-30. Studies identified in this review ranged from a mean low MMSE score of 19.0 to a mean high score of 25.8 (SD = 1.85).

Inclusion of Care-partners

While care-partner outcomes were not the focus of this review, it is important to highlight the extent of care-partner involvement in the interventions and their participation in evaluation and outcomes measurement. Care-partners are identified by the person with memory loss; this can be a family member or other identified support person. Seven of the eight studies reviewed

included care-partners in the intervention and collected outcome measurements specific to their experience and distinct from their partner with memory loss (Brodaty & Low, 2004; Gaugler et al., 2011; Joosten-Weyn Banningh et al., 2011; Laakkonen et al., 2016; Logsdon et al., 2010; Roberts, 2009; Waldorff et al., 2012). Care-partner outcomes were focused primarily on the domains of mood, adjustment to illness, self-efficacy for caregiving tasks, and caregiver burden. The investigations by Laakkonen (2016) and Brodaty and Low (2004) included measures of health service use by both care-partners and persons with memory loss. The study by Buettner and Fitzsimmons (2009) did not include care-partners in the programming but did rely on their proxy reports for several of the health outcomes measurements at the conclusion of the 12-week program. Care-partners also provided proxy reports in many of the studies for subjective measures of QoL, mood and self-efficacy. Specific outcomes measures for each study are referenced in Table 2.

Study Length and Measurement Time Points

Given the progressive nature of ADRD, it is perhaps not surprising that study lengths and time points of measurement across all studies were often quite short. Studies in this review had programs that ranged from 4 to 12 weeks, and measurement time points ranged from 4 weeks to 24 months. All studies collected measures at baseline and immediately following the program's conclusion. The investigation by Roberts and Silverio (2009) had a 3 month follow-up with participants. The longest post-intervention follow-up was provided by Laakkonen (2016) in an investigation of a group based self-management program for individuals with dementia and their spouses. Outcomes of health related quality of life, cognitive functioning were measured at 9 months post-intervention and health and social service use was measured at 24 months post-intervention.

Measured Outcomes for Participants

The most common outcome assessed for people with memory loss was depression, which was included in all but one study (Roberts, 2009). Also prevalent in interventions were measures of self-efficacy and self-esteem (Fitzsimmons, 2009; Logsdon et al., 2010; Roberts, 2009) and quality of life (Brodaty & Low, 2004; Laakkonen et al., 2012; Logsdon et al., 2010). Two studies included an assessment of service usage and cost effectiveness (Brodaty & Low, 2004; Laakkonen et al., 2016). Several studies captured emotional coping with the diagnosis, such as acceptance (Joosten-Weyn Banningh et al., 2011) and self-esteem (Fitzsimmons, 2009). Cognition was a measured outcome of three studies (Fitzsimmons, 2009; Laakkonen et al., 2016; Waldorff et al., 2012) The pragmatic outcomes of increased dementia knowledge and effectiveness of dealing with memory related issues were measured by two studies (Gaugler et al., 2011; Roberts, 2009) Four of the eight investigations in this review included proxy measurements by care-partners (Brodaty & Low, 2004; Fitzsimmons, 2009; Laakkonen et al., 2016; Logsdon et al., 2010; Waldorff et al., 2012). In most cases, the measures were collected from both the person with memory loss and the care-partners, and the degree of agreement or discrepancy between person with memory loss and their designated proxy was used to provide additional information about perceived outcomes.

Participant Outcomes

Despite overall similarities in program content across the interventions, participant outcomes were mixed. Improvements in psychological wellness, mood, and/or QoL were measured in seven studies. These outcome measures were significant in three investigations (Brodaty & Low, 2004; Fitzsimmons, 2009; Logsdon et al., 2010). However, four studies found no significant improvements in outcomes related to psychological wellness, mood, and/or QoL

(Gaugler et al., 2011; Joosten-Weyn Banningh et al., 2011; Laakkonen et al., 2016; Waldorff et al., 2012). Two studies reported significant findings in participant cognition (Fitzsimmons, 2009; Laakkonen et al., 2016). Logsdon et al. (2010) reported significant outcomes in family communication. Two studies reported no statistical significance in measured outcomes (Roberts, 2009; Waldorff et al., 2012). Participant satisfaction results show that programs were well received by individuals with memory loss (Gaugler et al., 2011; Roberts, 2009).

Discussion

The purpose of this review was to: a) evaluate the current focus of outcome measurement in these programs in the scientific literature; b) discuss participant and systems-level characteristics that make selecting outcome measures challenging; and c) develop recommendations about future directions of outcome measurement for early stage memory loss educational and support programs.

Results demonstrate that while the general concepts that were measured across studies were similar, the use of measurement tools varied across studies, making it difficult to directly compare outcomes. While there are an array of tools used to measure concepts such as QoL, mood, and self-efficacy, many of them are limited in their utility with older adults with memory loss. Inclusion of the person with memory loss as the informant and focus of measurement is an underdeveloped area of research (Marcantonio & Magaziner, 2009; Taylor, Demers, Vig, & Borson, 2012). Many potential outcome measures have not been validated with older adults and more specifically with those in the early stages of memory impairment. Two exceptions are QoL-AD and the Geriatric Depression Scale; both of these have psychometrics reported for individuals with dementia (Chang, & Edwards, 2010; Logsdon et al; 2002). The pragmatic challenges of memory loss, such as short term recall and communication deficits, do not

diminish the value of self-assessments that can provide insight into the subjective experiences of those with memory loss. They do however, challenge researchers to develop protocols and measures that accommodate these challenges. In addition, the studies reviewed here varied in their use of self-report vs. proxy report assessments. While both types of measures provide different perspectives in outcomes assessment, it is important that the perspective of the person with memory loss is included in the assessment. However, there are some challenges unique to this population. The degree of memory loss may have an impact on reports of factual information (for example, the number of occurrences of specific symptoms), but it does not appear to impair more subjective reports of general states (for example, statements about preferences or overall mood) (Black et al., 2012; Logsdon et al., 2002).

Substantial challenges to meaningful measurement with this participant population were elucidated as a result of this review inquiry. These challenges are in two domains; participant and systems level factors.

Participant Factors

Cognitive Factors

One of the overarching challenges with measurement is the progressive nature of ADRD. However, in the early stages this should present a relatively minor barrier to obtaining measurement outcomes from people with memory loss. Generally cognitive changes occur gradually, and the interventions that have been the focus of this review are between 4 and 12 weeks in length (Dröes, van der Roest, van Mierlo, & Meiland, 2011). The use of the MMSE as a cognitive screen across all studies helped to ensure participants were in the early stages of memory loss, and therefore able to participate in both the intervention and in the assessment process. Short term memory deficits are a reality of early stage ADRD. All of the interventions made reference to cognitive supports that were offered to help individuals succeed in the

programs. These included printed materials, review sessions, and having a care-partner present. Psychological factors such as depression and anxiety can exacerbate cognitive challenges. When individuals receive treatment for these conditions, either medically or through the therapeutic effect of the group process, cognition can improve (Caddell & Clare, 2011). Therefore, cognition should be assessed in psychosocial support and psychoeducational research, as either a direct or indirect outcome.

Psychological Factors

Memory impairment is often coupled with complex psychological factors that co-occur with the dementia diagnosis. Changes in mood such as depression, anxiety, and apathy are some of the most common co-morbidity in persons with dementia. Their presence can impede successful mechanisms of coping and adaptation to the disease (Palmer et al., 2010). Likewise, their presence may influence self-reported symptoms when the measurement tools require perception awareness. Depression and apathy are often undifferentiated by clinicians, and measurement tools are not commonly utilized to disentangle these two similar concepts, yet the development and utilization of measures that clinically distinguish these two syndromes may help inform future studies of early stage dementia interventions (Tagariello, et al., 2009). While apathy is a symptom of depression, not all who have apathy are depressed, and each may inhibit individuals from engaging in and benefitting fully from psychosocial support programs in different ways.

Lack of awareness and insight can also be a limiting factor in measurement. This concept is referred to clinically as anosognosia, a common phenomenon in ADRD (Rankin, Baldwin, Pace-Savitsky, Kramer, & Miller, 2005). It is characterized by lack of awareness of the disease progression and lack of insight into limitations in current functioning. For individuals with

dementia, it has been characterized as the inability of some individuals to update their sense of self as the disease progresses (Clare et al., 2012; Rankin et al., 2005). In other words, these individuals fail to have insight and awareness of changes in mood, personality and memory. When measuring subjective experiences that require introspective analysis this can impact the validity of the results.

The presence of these psychological factors can be a barrier to accurate outcome measurement. In self-reported measures, individuals with depression, anxiety and apathy are likely to perceive their performance on activities in the program differently.

System Level Factors

Dementia care pathways are currently not well defined in the health care system, and medical personnel that engage with individuals during the diagnostic process are often not aware of support systems and educational opportunities available for individuals with memory loss (Manthorpe, 2014). Post-diagnosis, many individuals struggle on their own to find the support they need (Bossen et al., 2009).

Advances in science that have increased early ADRD diagnostic abilities, as well as health initiatives such an annual memory screen for Medicare recipients, are encouraging the early identification of ADRD. Although it has been suggested that early diagnosis provides opportunities for involvement in long term planning, and that early stage psychosocial programs may facilitate planning, as well as engaging and acclimating diagnosed persons to larger support networks (Iliffe, Manthorpe, & Eden, 2003), these outcomes were not evaluated in the studies included in this review. With the potential for individuals with ADRD to be living in the community for years after their diagnosis it is important that these outcomes be considered in future investigations.

Proxy Measures

A proxy informant is typically a spouse, close family member or friend who provides answers to measurement questions. Proxies are often used in measuring outcomes for individuals with ADRD, due to the presumed inability of the person with dementia to respond accurately to questions about their own functional and psychological status (Sheehan, 2012). However, many researchers have argued and provided evidence that individuals with early stage dementia can accurately report about their own affect and quality of life (Logsdon, 1999; Moniz-Cook et al., 2008). Thus, it appears possible and appropriate to obtain measures from both the person with memory loss and their care-partner in early stage dementia interventions. Although this may reveal discrepancies between the person with dementia and the care-partner, the nature and degree of such discrepancy is a source of rich information for researchers (Votruba, Persad, & Giordani, 2015). This information can be used to inform and more accurately tailor early stage interventions. A substantial body of research has been assembled that looks at the degree of discrepancy that is presented in self-rated outcomes from people with dementia and the ratings of a proxy in outcomes such as depression, self-efficacy, and affect (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004). Most notably, is the 2008 European Consensus document which rigorously examined the feasibility and psychometric properties of outcomes measures used in psychosocial intervention research with people with dementia (Moniz-Cook et al., 2008).

Specifically, they examined the outcomes measures of QoL, mood, global functioning, behavior, and daily life skills for the person with dementia. This review highlights the need for researchers to carefully choose measures that are sensitive yet show reliability in reporting the subjective measures of QoL, mood, and other person-centered outcomes that are the focus of early stage psychosocial intervention research. It is also important to understand the contextual

challenges such as relationship dynamics that can inhibit accurate proxy measurement (Boyer et al., 2004).

Conclusion

The number of people with ADRD will continue to grow as our population ages (World Health Organization, 2012), and in the absence of effective pharmacological interventions, psychosocial programs for people with early stage memory loss will increasingly be an important part of post-diagnostic support and care. While efforts have been made to decrease stigma and increase availability and referral to post diagnostic programs, the number of people who participate in these interventions remains small (Leung, Orrell, & Orgeta, 2014). Outcome measurement is an important element to ensure that interventions are relevant and effective in helping diagnosed persons live healthy and productive lives. It is also important that researchers collaborate and share information (Moniz-Cook et al., 2008). Collectively, this knowledge has the power to impact the lives of millions of individuals diagnosed with ADRD, and to help them live well despite their diagnosis. This is where the impact of the outcome becomes truly critical.

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Chapter 3

Living alone with dementia: the effect of self-efficacy, mood, and quality of life on the concept of wellbeing.

Abstract

It is estimated that a quarter of those with Alzheimer's disease and related disorders (ADRD) live alone in the community. Special challenges exist in meeting the unique needs of these individuals yet little is known about this population. This research examines differences between individuals who live alone compared to those who live with a care partner. The study sample consisted of 144 individuals with early memory loss, 43 of whom lived alone in the community. Demographic characteristics and measures of self-efficacy, mood, and quality of life were compared between the two groups. Multivariate analysis of variance examined differences between groups on these three measures and on their contributions to a global construct of well-being. Results showed no significant differences between the two groups on the three outcome variables of interest. Community based programs for persons with early stage memory loss typically focus on dyads. Knowledge of the characteristics and wellbeing of individuals who live alone will help to inform future development of programs for this growing and underserved group. The similarities across both of these groups necessitate additional research into the needs of those not represented in the sample and who represent the diverse socio-economic profile of individuals living with ADRD.

Keywords: Alzheimer's, ADRD, Dementia, early stage, living alone.

Introduction

Alzheimer's disease and related dementias (ADRD) represent a growing public health epidemic affecting approximately 5 million Americans. This number is anticipated to swell to 13.8 million by 2050 (Alzheimer's Association, 2014). Increased public knowledge about the early signs of memory loss coupled with advances in diagnostic capabilities has resulted in more individuals receiving a probable confirmation of the disease in the very earliest stages. Changes in health care policies have further encouraged the push for early identification (Khachaturian, 2012). Individuals who are diagnosed in the early stages of memory loss are increasingly seeking information both about the disease progression and about how to live well despite the diagnosis (Bunn et al., 2012).

ADRD disorders eventually result in a progressive loss of functioning and dependency on others to complete activities of daily living (ADLs). However, in the early stages of the disease many individuals remain both cognitively capable and functionally able to continue to actively engage in their usual activities, and many individuals choose to continue living independently in their own homes or in independent senior retirement communities. It has been estimated that nearly 35.4 % of individuals with dementia live alone in the community, and as the number of individuals diagnosed with a dementia disorder continues to grow, even more of those individuals will be living alone (Alzheimer's Association, 2012). Previous studies suggest that individuals with dementia who live alone are at greater risk of health complications and have fewer social connections than those living with a partner (Miranda-Castillo, Woods, & Orrell, 2010; Wattmo, Londos, & Minthon, 2014) For example, Miranda-Castillo (2010) found that individuals who lived alone were isolated and had more challenges related to self-care than their

peers with care partners. The progressive nature of the disease coupled with social isolation puts individuals at risk of self-neglect and potentially abuse by others (Miranda-Castillo et al., 2010). Overall, the progressing nature of the disease can impact an individual's well-being.

Well-being is a concept that represents the collective impact of multiple personal level factors that contribute to one's overall perception of health (Kendig, Browning, Young, & Young, 2016). Well-being is commonly characterized as a state of being content with one's current state of mental and physical health. Well-being is further impacted by social networks and personal resources (Karademas, 2006). A positive perception of overall well-being can exist despite a chronic or progressive disease (Folkman & Greer, 2000). Cognitive and functional capacities represent two important factors that contribute to one's perception of total well-being. Thus, it is reasonable to conjecture that a cognitive or functional change might decrease perceived well-being. Additional indicators, such as perceptions of self-efficacy, mood, and quality of life (QoL) by the person with memory loss are also important indicators of overall well-being that may be impacted by the person's living situation and availability of a supportive care partner.

This investigation aims to expand our understanding of factors that contribute to well-being in individuals with early stage dementia, and to investigate differences in well-being among individuals living alone compared to those who do not live alone. Baseline demographic and descriptive data were investigated along with three outcome measures, self-efficacy, depression, and quality of life, which were hypothesized to be associated with a global construct of "well-being." Living status (alone vs. with care partner) was investigated to determine whether well-being and its components differed between the two groups.

Methods

Study Design

This investigation was a secondary examination of data collected at baseline from 144 participants enrolled in a randomized controlled trial of a structured 8-session Early Stage Support Group. Detailed descriptions of the study intervention have been previously published (Logsdon et al., 2010; Logsdon et al., 2006). The original study was collaboration between University of Washington researchers and the Western and Central Washington Chapter of the Alzheimer's Association. The Alzheimer's Association provides a range of education and support programs including a telephone helpline for individuals who have concerns about memory loss. Individuals who sought services of the Association were informed of the study and referred to study coordinators. All individuals who were interested in participation were contacted and screened for eligibility by the University of Washington's research study coordinator.

Eligibility Criteria

Inclusion criteria for individuals with memory loss included acknowledgement of memory loss, diagnosis of ADRD by healthcare provider and/or self-reported signs and symptoms of ADRD, and an MMSE score ≥ 20. Additionally, participants needed to reside in the community or in an independent retirement complex, speak English, and able to commit to attending all sessions of the intervention.

Measures

All measures were collected in an interview format by a trained member of the research staff. Participants with memory loss were interviewed independently of their care partners, to

ensure that their self-reported responses reflected their own perception and were not influenced by their partner. All participants were assessed utilizing a scripted interview protocol that included descriptive demographics. Cognitive status was measured by the Mini-Mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975). Self-report measures were used to assess self-efficacy, mood, and quality of life.

Collectively, self-efficacy, mood and quality of life are believed to contribute to the construct of total "well-being" for an individual in the early stages of dementia. Each of these has a bi-directional relationship and impact on one another (Figure 3.1). Self-efficacy, mood, and quality of life measures are commonly utilized across many psychosocial interventions for ADRD (Moniz-Cook et al., 2008).

Self-Efficacy

Self-efficacy is the belief an individual has about their own ability to manage tasks that are related to their well-being. In the presence of a life-altering diagnosis an individual's self-efficacy beliefs have been identified as critical to both health maintenance and enhancement behaviors (Karademas, 2006). Measures of self-efficacy have been utilized in multiple health related self-management programs. A measure of self-efficacy was utilized to study the effectiveness of a community-based self-help intervention for Korean Americans with Type 2 Diabetes. Self-efficacy was a significant predictor of adherence to a diabetes specific management regime (Kim et al., 2015). In a study of a self-management program intervention for cancer survivors with ostomies, self-efficacy beliefs significantly positively impacted participant's self-care routines (Krouse et al., 2016). Likewise, a program of education and support for people with chronic heart failure found that increasing self-efficacy though a nurse

lead intervention increased participants' self-care success (Clark et al., 2015). These interventions represent the usage of self-efficacy for the most common chronic illnesses afflicting older adults; diabetes, heart disease and cancer. Dementia studies that have utilized self-efficacy have generally focused on measurement of self-efficacy beliefs for the care partner. This often represents the later stages of the disease when the care partners are more engaged in daily care management. Self-efficacy has had limited utilization in early stage dementia interventions for the person with memory loss. However, individuals with early stage dementia are often actively engaged in their own health promoting behaviors. Self-efficacy has been found to be a significant predictor of quality of life for individuals with early dementia who participated in an 8-week early stage dementia support program (Logsdon et al., 2010).

The self-efficacy measure used in the current investigation was developed and validated with input from Alzheimer's Association staff and volunteers. It is a 12-item questionnaire that asks informants to rate their feelings of self-efficacy on a scale of 1-10. One indicates not confident and 10 indicates very confident. The twelve item questionnaire identified domains that were critical to adaptation and management of a progressive memory loss disorder which included accessing resources, communicating needs, and making decisions about current and future needs.

Quality of Life

An individual's subjective assessment of their physical and mental health contributes to an overall perception of "Quality of Life." A number of measures have been developed to measure this construct specific to individuals with dementia (Moniz-Cook et al., 2008). QoL perception has been found to have a strong relationship with depressed mood (Logsdon, et al, 2001, Woods et al., 2014). This is especially critical for individuals who live alone (Charles,

Naglie, Lee, Moineddin, & Jaglal, 2015). Decreased quality of life coupled with depression can increase and exacerbate social isolation and increase incidents of self-neglect (Charles et al., 2015).

For this investigation, quality of life was measured using the QOL-AD, a widely used measure that was specifically developed and validated with older adults with cognitive impairment (Logsdon, 1999). Internal reliability (alpha=.89), and test retest reliability (kappa= .92) are excellent, and validity is supported by its correlation with related constructs (Logsdon, Gibbons, McCurry, & Teri, 2002). It consists of 13 items that ask respondents to subjectively rate their current feelings about various constructs related to QoL, including physical health, mood, social and family relationships, ability to engage in desired activities, self-esteem, and overall quality of life.

Mood

Significant alterations in mood and the presence of depression are reported to be common in early stage dementia (Votruba, Persad, & Giordani, 2015). Clinical depression is characterized by reduced interest and pleasure in activities (Lam et al., 2010; Logsdon & Teri, 1997; Teri & Uomoto, 1991). Depressed mood has shown to be correlated with decreased QoL as well as decreased self-efficacy (Logsdon et al., 2002; Robinson-Smith et al., 2000; Woods et al., 2014).

Mood was measured utilizing The Geriatric Depression Scale Short Form. Scores > 5 are suggestive of depression and scores ≥ 10 are considered positive for depression in older adults. This tool has been validated extensively in geriatric populations and shows strong internal reliability and validity (Sheikh & Yesavage, 1986). It has also been shown to have acceptable

psychometric validity as a self-report measure in individuals with cognitive impairment (Logsdon et al., 2002).

Statistical Analysis

A baseline interview and demographic profile was collected on all participants, including presence of co-morbid chronic conditions and cognitive status. Data were examined to more fully understand how gender, education, and cognitive status differed across the two groups represented in the sample.

A comparative analysis of group differences was executed to examine the baseline differences between those living alone and those living with a care-partner. A multivariate analysis of variance (MANOVA) procedure was utilized to examine whether mean differences existed between groups. MANOVA linearly combines all the dependent variables, maximizing the differences between the groups. MANOVA is an appropriate method of analysis for comparing two groups on multiple metrical outcomes (Tabachnick & Fidell, 2007).

Additionally, MANOVA is a good option for comparing groups on an emergent variable. In this study the dependent variables contributed additively to the total construct of well-being. There were three continuous dependent variables: self-efficacy, mood, and quality of life. There was a single independent variable with two levels; living with a care partner and living alone. The original sampling plan was examined to confirm that subjects were independent of one another and that there was no threat of nesting or clustering within the sample. SPSS software version 16 was used to perform all analyses. Significance was set at .05 for all analysis.

Results

Participant Sample

The original sample of 144 was reduced to136 after excluding cases based on incomplete data. If participants had not completed one of the three outcome measures at baseline they were excluded from final analysis. This resulted in exclusion of 3 individuals who lived alone, and 5 individuals who lived with care partners. The independent variable of living situation included two levels and had 96 participants who lived with a care-partner and 40 who lived alone. Table 1. details the baseline demographics of participants in both groups. An independent-samples t-test was conducted to compare demographic variables between the two groups. There was a significant difference in age and gender. Those who lived alone were significantly older (M= 78.34, SD= 8.67) than those who lived with a care partner (M=74.34, SD=9.31); $t\ (134)$ =2.16, p = 0.03, and those who were living alone were more likely to be female (83%) compared to those living with care partners (42%), (Fisher's exact test < .001).

The groups did not differ on the best linear combination of the multivariate construct "well-being" (Wilkes's $\lambda = 0.09$, $F\ (2,132) = .880$, $p = .454$, partial $\eta^2 = 0.020$). Follow-up univariate analysis of variance tests using Bonferroni adjustment showed that the two groups did not differ from each other significantly on each of the outcomes (Table 2). The MANOVA assumptions of homogeneity of variance covariance matrices, multivariate normality, linearity and independence of observations were examined and no violations existed. Box's M-test for homogeneity of variance covariance matrices is tenable at $p = .132$. Examination of histograms

concurred that normality was met. Linearity was met through examination of scatter plots and observations were independent with no nesting or clustering.

Discussion

The purpose of this investigation was to determine if there were any baseline differences in well-being as a composite construct of three self-assessed outcomes of self-efficacy, mood, and quality of life for individuals in the early stages of memory loss based on living situation. The results of the MANOVA showed that there were no statistically significant differences in the composite of these measures for individuals based on living situation. Additionally, there were no differences found in the follow-up univariate analysis of variance (ANOVA) for each of the individual outcome measures.

Principal Finding

Collectively the concepts of self-efficacy, mood, and QoL were used to provide an assessment of overall well-being for persons with early stage memory loss. Well-being was hypothesized to differ for persons living alone vs. those living with a care partner. The MANOVA analysis produced non-significant differences amongst the two groups on overall well-being as well as on the three component outcome variables.

Significance of Findings

The study sample consisted of 136 community residing individuals with early stage dementia, 40 of whom participated in the study without a care partner. Those individuals living alone represent a sizable sample of a hard to reach population that has had little representation in the scientific literature, thus providing an opportunity to examine their unique characteristics and challenges. We currently know very little about individuals in the early stages of memory loss

who live alone and are proactively seeking education and support services. Prior studies have looked at the impact of education and support on dyads, with a strong emphasis on the impact specifically for the care partner (Moon & Adams, 2012). This investigation differs from prior studies by specifically analyzing the baseline characteristics of individuals with early stage ADRD who live alone and seek these support mechanisms. To our knowledge this is the first time these collective measures have been analyzed in regards to individuals living alone with ADRD. As the population of individuals diagnosed with ADRD grows it will be important to assess and respond to the unique challenges that arise due to differences such as living situation. All participants in this investigation were drawn from the local geographical area. Furthermore, each individual actively sought participation in these groups, and, considerable effort, engagement, motivation and knowledge of this resource pathway was required on the part of the potential participants. Participants were primarily white, had high levels of education and had similar MMSE scores. The mean scores for the measures of self-efficacy, mood, and quality of life were not significantly different between groups. These results represent a single assessment in the early stages of ADRD; it is not known how these results might change over time for individuals respective of their living situation. It is important to not infer from these results that there are no differences in the population of individuals living alone and those living with a care-partner. Research with early stage persons has been limited by small samples and largely homogenous populations. This has limited our scope of understanding the complexities of living with a memory loss disorder within a diversity of socio-economic conditions.

The clinical significance of living alone in the community in the early stages of dementia is an area that deserves further study. The trajectory of an ADRD diagnosis is one of diminishing ability and increasing dependence on care and support networks. However, there

may be variability how long individuals maintain the ability to live alone in the community, depending on disease progression, co-morbid conditions, and socio-environmental factors such as living environment, resources, and ability to engage a support network. For individuals who live alone and have limited support from familial or informal network such as friends and neighbors there will be a greater need during the early stages of the disease to establish formal networks and to formulate contingencies for care provision as the disease progresses. The demographic profiles of this current sample showed that 40% of the living alone group was living in congregate living situations such as retirement communities and senior housing. The extent of support provided to these individuals is unknown. However, it would be reasonable to hypothesize that living in a setting which has the potential to provide support services in the future and an extended network of social support could positively impact measures of self-efficacy, mood, and QoL. In addition, proactively procuring congregate living early in the disease process might increase perceptions of wellness. However, the high cost of supportive living limits the availability of this resource to individuals with financial resources. Alternatively, individuals who live alone in the community and have limited social networks risk being more severely compromised both in areas of medical and psychosocial need due to isolation, limited resources, and the progressive nature of memory loss. All of these limitations might limit their access to services as their cognitive ability declines. In the partnered group 93% lived in a private residence, where support was provided primarily by a family care partner. The advantage of congregate living might also extent to partnered individuals, though the extent of this impact needs additional study. Culminations of cultural and socio-economic factors contribute to an individual's assessment of well-being. Additional investigation into these mediators is warranted.

Limitations

As a secondary study, this investigation was limited to the measures that were collected as part of the original study. Self-efficacy, mood, and QoL represent one composite of selected factors that can contribute to the overall conceptualization of well-being in individuals. In future studies, additional measures specific to the construct of well-being could increase the precision in measuring the impact of this construct on individuals with memory loss and the development of evidence based community interventions. The current sample was relatively homogeneous, primarily well-educated, Caucasian, and living in an urban area with a wide range of available resources. Additional information is needed on the needs of underserved ethnic and racial groups, on those with lower educational attainment, and on those living in areas with less access to medical and social service resources.

Conclusion

Psychosocial interventions that provide education and support to newly diagnosed individuals are increasingly an area of focus of public policy. Facilitated by the passage of the National Alzheimer's Project Act, 44 states have adopted or are in the process of adopting a state plan to address ADRD (U.S. Department of Health & Human Services, 2015). A domain of focus on actions related to "Early Diagnosis and Detection" is a part of many of these plans (Fargo et al., 2014). However, wide variation exists in the state action plans related to early stage psychosocial interventions. As we continue to develop and bring evidence based practices to community settings we need to remain cognizant of the differences that are experienced by individuals. Socio-economic factors may contribute greatly to the experiences of individuals with dementia who live alone. A larger, prospective longitudinal study designed specifically to

explore differences in cognitive status, functional ability, and well-being in a more heterogeneous sample of persons with early stage ADRD, with and without partners, living in various residential settings, would be invaluable to identify differences in service use, needs, and outcomes among these groups.

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Table .1.1 Studies excluded with reason (N=8)

Study	Reason
Cheston and Howells (2015)	Sample size n < 20 (n=8)
Fitzsimmons and Buettner (2003)	Sample size n < 20 (n=7)
Goldsilver et al (2001)	Evaluation only, no outcome measures for participants
Ingersoll-Dayton et al (2013)	Feasibility, qualitative
Judge et al (2010)	Evaluation only, no outcome measures for participants
Logsdon (2006)	Preliminary report of study data
Whitlatch et al (2006)	Evaluation, qualitative data only
Zarit et al, (2004)	Evaluation, qualitative data only

Table 1.2 Reported Sample Characteristics (N=10)

Author(s) Primary Location	**Study Design Sample (Intervention/Control)**	**MMSE Baseline Mean**	**PWD Gender**	**CP (% Spouse)**	**Race Ethnicity (Author categorized)**	**Recruitment Source**
Brodaty and Low (2004) New South Wales, Australia	Single group N=24 dyads	25.8	Female: 25% Male: 75%	100%	NR	Alzheimer's Association
Buettner and Fitzsimmons (2009) Florida, USA	Two Group N=89(56/33)	25.6	Female: 46% Male: 54%	NCP	NR	Alzheimer's Association
Gaugler et al., (2011) Minnesota, USA	Single Group N=124 63 PWD 61CP	24.67	Female: 52% Male: 48%	82%	White 96.7%	Alzheimer's Association
Joosten-Weyn Banningh et al., (2011) Netherlands	Non-randomized Wait-list control N=93 (63/30)	25.8	Female: 47% Male: 53%	90.4%	NR	Memory Clinics
Laakkonen et al. (2016) Finland	RCT N=136 (67/69)	19.9	Female: 37% Male: 63%	100%	NR	Memory Clinics

Author(s) Primary Location	Study Design Sample (Intervention/Control)	MMSE Baseline Mean	PWD Gender	CP (% Spouse)	Race Ethnicity (Author categorized)	Recruitment Source
Logsdon et al., (2010) Seattle, USA	RCT N=142 (96/46) Dyads	23.4	Female: 48% Male: 52%	80%	White 97%	Alzheimer's Association
Marshall et al (2014) South Hampton,UK	Pilot RCT N=58 (28/30)	23.6	Female: 64% Male: 36%	32%	White British 96.4% Canadian 3.6%	Memory Clinics
Quinn et al (2016) North Wales, UK	Pilot RCT N=24(13/11) Dyads	23.5	Female: 23% Male: 77%	77%	UK Nationality 92% Other 8%	Memory Clinics
Roberts et al. (2009) Boston, USA	Single group N=74 dyads	23.8	Female: 27% Male:73%	81%	White 100%	Alzheimer's Association
Waldorff et al. (2012) Denmark	RCT N=330(163/167)	24.1	Female: 53% Male: 47%	63.8%	NR	Memory Clinics

Note: MMSE= Mini Mental Status Exam, CP= Care partner, NR=not reported, PWD= Person with dementia, RCT= Randomized Control Trial, NCP= No Care partner participation

Author(s)	Name of Program/ Program components (as provided by authors)	Education	Peer Support	Individuall y Tailored	Dyad based
Brodaty and Low (2004)	Making Memories 8 weekly, 2 hour sessions education for PWD and CP. 1 couple based counseling session with diversional therapist 10 weekly activity based groups for PWD, support group session for CP	X	X	X	X
Buettner and Fitzsimmons (2009)	Health Promotion Course 12 weekly, 2 hour session for PWD only No session information	X			
Gaugler et al., (2011)	Memory Club 10-13 weekly sessions, 90-120 minute sessions 3 sites with unique offerings (categories- leave)	X	X		X
Joosten-Weyn Banningh et al., (2011)	Group Therapy for patients with mild cognitive impairment 10 weekly, 120 minute sessions, (jointly with PWD +CP) Weekly content description not provided	X	X		X
Logsdon et al., (2010)	Early Stage Memory Loss Support Group 8 weekly, 90 minute sessions (joint and separate sessions for PWD+CP) 1. Introduction/Overview 2. Coping with Memory Loss 3. Medical Update: Diagnosis, Treatment and Research 4. Social and family relationships 5. Daily living skills 6. Self-esteem 7. Planning for the future	X	X		X

	8. Legal and financial considerations 9. Health considerations and stress management		
Marshall et al (2014)	Living Well with Dementia 10-weekly, 75 minute sessions (CP attend only first and final session) 1.Welcome and Introductions 2. Problems and Frustrations 3. Memory Aids and Strategies 4. Finding a way through feelings 5. Coping with stress 6. Friends and family, health professionals, and strangers 7. What is dementia 8. Living as well as you can 9. Staying active 10.Bringing it all back together	X	X

Quinn et al. (2016)	Self-Management Groups 8 weekly, 90 minute sessions (CP at beginning and end of sessions) 1. Information about dementia. 2. Enjoying favorite activities & interests. 3. Staying well 4. Practical ways to manage memory difficulties 5. Maintaining relationships 6. Planning for the future 7. Coping skills 8. Local resources	X	X	X
Roberts et al. (2009)	Taking control of Alzheimer's Disease: Techniques for Early-Stage Patients and their Care-Partners. 4 weekly, 2 hour sessions 1.Introduction and Overview of dementia 2.Memory Aids, Treatment, breakout support/discussion sessions 3.Mental exercises, driving issues, legal and financial planning, reaction to diagnosis and sharing the diagnosis 4. Support services, advocating with physicians, volunteer opportunities, changing roles and relationships, breakout support/discussion session.	X	X	X

Waldorff et al. (2012)	Counseling, education, and peer based support. Individualized Counseling Support Sessions at the beginning of the program end of the program, and 1 optional network session. (PWD + CP separately) 5 week, 2 hour education and support sessions. (Separate) 1.General information about dementia 2.Legal considerations 3.Living with dementia 4.Support needs 5.Summary of sessions Information folder Outreach phone counseling.	X	X	X	X

Table 2.1 Outcome Measures for Psychosocial Support and Psychoeducation Interventions (N=8)

Author (s) Study Design Location	**Participant Characteristics (SD)**	**Intervention Description**	**Participant Outcome Measures *denotes proxy measures**	**Measurement Time points**	**Participant Outcomes**
Brodaty and	N=24 dyads	"Making Memories"	**Psychological Wellness**	Baseline	**Psychological Wellness**

Author (s) Study Design Location	Participant Characteristics (SD)	Intervention Description	Participant Outcome Measures *denotes proxy measures	Measurement Time points	Participant Outcomes
Low (2004). Single Group Australia	MMSE mean: 25.8 (3.7) Age mean PWD: 71	Multi-component Program combining elements of education, behavior modification and support for PWD and Caregiver. 8 weeks/2 hour sessions	General Health Questionnaire GHQ-12* (PWD and Caregiver rated) **Quality of Life** European Quality of Life visual analogue thermometer. *(caregiver rated)	9 weeks 24 weeks	Significant decreased in GHQ-12 scores for PWD (p = 0.005)
Buettner and Fitzsimmons (2009). Two Group USA	N= 89 (56/33) Intervention Group MMSE mean: 25.6 (SD not reported) Age Mean PWD: 81 Control Group MMSE mean: 26.64 (SD not reported)	Health Promotion Course 12 weeks/ 2 hour sessions	**Cognition** MMSE **Depression** Short-form Geriatric Depression Scale (GDS) **Self-efficacy** Matthias and Schwarzer General Self-Efficacy Scale **Self-esteem** Rosenberg Self-Esteem Scale. **Quality of Life** Perceived Quality of Life Scale **Health Report**	Baseline 12 weeks	**Cognition** Significant increase in MMSE scores for treatment group (p <0.05) **Depression** Significant reduction in depression for treatment group. (p<0.000)

Author (s) Study Design Location	Participant Characteristics (SD)	Intervention Description	Participant Outcome Measures *denotes proxy measures	Measurement Time points	Participant Outcomes
	Age mean: 78		Delirium and adverse drug events* Social engagement & recreational activities * Support networks established* Physical functioning Exercise participation* Incidents of falls* Nutritional Change Safety Procedures*		
Gaugler et al. (2011). Single Group USA	N=124 (63 PWD/61 CP) MMSE mean: 24.67 (SD not reported) Age mean: 63	"Memory Club" Education and support 10-13 weeks/90-120 minute sessions	**Effectiveness** Pre/Post survey of effectiveness in dealing with memory related issues. **Depression** Geriatric Depression Scale (GDS) **Satisfaction** Satisfaction Survey	Pre/Post (dependant on program length)	**Depression** No significant findings.
Joosten-Weyn Banningh et al. (2011). Non-randomized Wait-list	N= 93 (63/30) Intervention Group MMSE mean:	Group Therapy for MCI patients and significant others 10 weekly/ 2 hour	**Acceptance** Illness Cognition Questionnaire Subscales (ICQ) **Distress** Geriatric Depression	2 weeks-Pre-Intervention 2 weeks- Post-Intervention	**Acceptance** Significant increases in acceptance of cognitive impairment by those with MCI (p=0.034).

Author (s) Study Design Location	Participant Characteristics (SD)	Intervention Description	Participant Outcome Measures *denotes proxy measures	Measurement Time points	Participant Outcomes
control Netherlands	25.6 (3.2) Age Mean:71 Control Group MMSE mean: 25.8 (3.9) Age Mean: 70	sessions	Scale-Short Form (GDS-15) **Wellbeing** RAND-36 Health Survey subscales **Helplessness** Illness Cognition Questionnaire Subscales(ICQ)		**Distress and Wellbeing** No significant findings
Laakkonen et al (2016). RCT Finland	N=134 (67/67) Intervention Group MMSE Mean: 19.9 (5.7) Age Mean: 77 Control Group MMSE Mean: 21.7 (3.7) Age Mean:77	Group based self-management program for PWD and Spouses. 8 weeks	**Health Related QoL** 15D **Cognitive Function** Verbal Fluency (VF) Clock Drawing Test (CDT) **Health & Social Service Use** Medical Records Screening	Baseline 3 months 9 months 24 months (social service use measures only)	**Health Related QoL** No significant findings **Cognitive Functioning** Significant improvement in CDT and VF at 9 months. **Health and Social Service Use** No significant change, intervention was cost neutral.
Logsdon et al., (2010) RCT	N= 142 (96/46) dyads	Structured early-stage memory loss support group program.	**Quality of Life** QoL-AD* (PWD and Caregiver rated)	Baseline post-treatment	**Quality of Life** Participants has significant increase in

Author (s) Study Design Location	Participant Characteristics (SD)	Intervention Description	Participant Outcome Measures *denotes proxy measures	Measurement Time points	Participant Outcomes
USA	Intervention Group Age mean: 77 MMSE mean: 23.2 (4.7) Control Group Age mean: 70 MMSE mean: 24 (3.8)	9 weekly/90 minute sessions	**Health Related- QoL** SF-36* (PWD and Caregiver rated) **Mood** The Geriatric Depression Scale (GDS)* (PWD and Caregiver rated) **Family Communication** Family Assessment Measure* (PWD and Caregiver rated) **Self-efficacy** The self-efficacy scale* (PWD and Caregiver rated)		QoL- AD scores ($p<.001$). **Mood** Participants showed significant increase in GDS scores ($p<.01$). **Family Communication** Significant increases in family communication ($p< .05$) **Self-efficacy** Significant improvement for participants who also had significant QoL improvement. *($p<.01$)*
Roberts and Silverio (2009) Single Group USA	N= 74 dyads MMSE mean: 23.8 (3.9) Age mean : 74	"Taking Control of Alzheimer's Disease" Education and support program	**Participant Satisfaction** **Self-efficacy (coping)** Merluzzi's Measure of illness self-efficacy.	Pre/Post 3 month follow-up	No significant findings

Author (s) Study Design Location	Participant Characteristics (SD)	Intervention Description	Participant Outcome Measures *denotes proxy measures	Measurement Time points	Participant Outcomes
		4 weekly/ 2 hour sessions	(Modified) **Dementia Knowledge** 22 item true/false measure		
Waldorff et al. (2012) RCT Denmark	N= 330 (163/167) Intervention Group MMSE mean: 24.0 (2.5) Age mean PWD: 77 Control Group MMSE mean: 24.1 (2.7) Age mean PWD: 76	Tailored counseling and disease education. 5 weekly/ 2 hour sessions	**Cogniton** MMSE **Depression** Cornell depression scale for dementia.* (Clinican rated based on interviews with PWD +CP) **Quality of Life** European quality of life visual analog scale (EQ-VAS)* (PWD+CP) QoL-AD* (PWD+CP)	Baseline 6 months 12 months	Found no significant change outcomes.

Note: CP = Care Partner; MMSE=Mini Mental Status Exam; MCI= Mild Cognitive Impairment; PWD = Person with Dementia; QoL= Quality of Life.

Table 2.2 Studies Excluded after Full Text Review (N=10)

Study	Reason
Cheston and Howells (2015)	Sample size n < 10 (n=8)
Fitzsimmons and Buettner (2003)	Sample size n < 10 (n=7)
Goldsilver et al (2001)	Evaluation only, no outcome measures for participants
Ingersoll-Dayton et al (2012)	Feasibility, qualitative
Judge et al (2010)	Evaluation only, no outcome measures for participants
Marshall (2014)	Pilot
Logsdon (2006)	Preliminary report of study data
Quinn (2016)	Pilot
Whitlatch et al (2006)	Evaluation only, qualitative data only
Zarit et al, (2004)	Evaluation only, qualitative data only

Table 3.1. Baseline Characteristics of participants living with memory loss by living situation

Characteristic	Alone	Partnered Living	Combined
Participants	N=40 (29)	N=96 (71)	N=136
Age in years, mean *(SD)*	78 (8.67)	74 (9.31)	75 (9.25)
MMSE, mean *(SD)*	25 (3.60)	22 (4.65)	23 (4.49)
Sex			
Male	7 (17)	56 (58)	63 (46)
Female	33 (83)	40 (42)	73 (54)
Race/ethnicity			
Native Hawaiian, Pacific Islander	1 (2)	2 (2)	3 (2)
Hispanic	0	1 (1)	1 (1)
White	39 (98)	93 (97)	132 (97)
Marital Status			
Married	1 (2)	82 (86)	83 (60)
Widowed	23 (58)	7 (7)	30 (22)
Separated	2 (5)	0	2 (2)
Divorced	14 (35)	5 (5)	19 (14)
Never Married	0	1 (1)	1 (1)
Other	0	1 (1)	1 (1)
Education			
No high school	1 (3)	0	1 (1)
Some high school	3 (7)	2 (2)	5 (4)
High School Graduate	4 (10)	14 (15)	18 (13)
Some College	10 (25)	21 (22)	31 (23)
College Graduate	8 (20)	22 (23)	30 (22)
Some Graduate School	3 (7)	9 (9)	12 (9)
Graduate Degree	9 (23)	22 (23)	31 (23)
Vocational/Tech Graduate	2 (5)	6 (6)	8 (5)
Living Situation			
Assisted Living	4 (10)	-	4 (2)
Private Residence	24 (60)	89 (93)	113 (84)
Retirement Community	7 (18)	7 (7)	14 (10)
Senior Housing	5 (12)	-	5 (4)

Notes: MMSE= Mini-Mental State Exam

Table 3.2. Baseline Measurement Outcomes

Outcome Measure	Alone (N=40)	Partnered (N=96)	Total Combined(N=136)
Self-efficacy	7.77 (1.33)	8.10 (1.33)	8.00 (1.38)
QoL-AD	38.08 (5.41)	38.82 (6.11)	38.60 (5.90)
GDS	3.40 (3.27)	3.36 (3.20)	3.37 (3.21)

Notes: QoL-AD= Quality of Life Alzheimer Disease, GDS=Geriatric Depression Scale

Table 3.3

MANOVA with Univariate Follow-Ups

Measures	Group 1 n = 40		Group 2 n = 96		Group 1 + 2 n= 136		Group 1 vs. 2	
	M	*(SD)*	*M*	*(SD)*	*M*	*(SD)*	*F*	*ES*
Well-being							*0.88 (2,132)*	*.02*
QoL-AD	38.09	(5.41)	38.82	(6.11)	38.60	(5.90)	0.43 (1,134)	.01
SE	7.77	(1.48)	8.10	(1.33)	8.00	(1.38)	1.71 (1,134)	.00
GDS	3.40	(3.26)	3.36	(3.20)	3.37	(3.21)	0.01 (1,134)	.00

Note: QoL-AD = Quality of Life Alzheimer's Disease; GDS = Geriatric Depression Scale. Effect size for multivariate tests is partial eta-squared.

* $p < 0.05$; all p s for univariate follow-up tests are adjusted for multiple comparisons using Bonferroni correction.

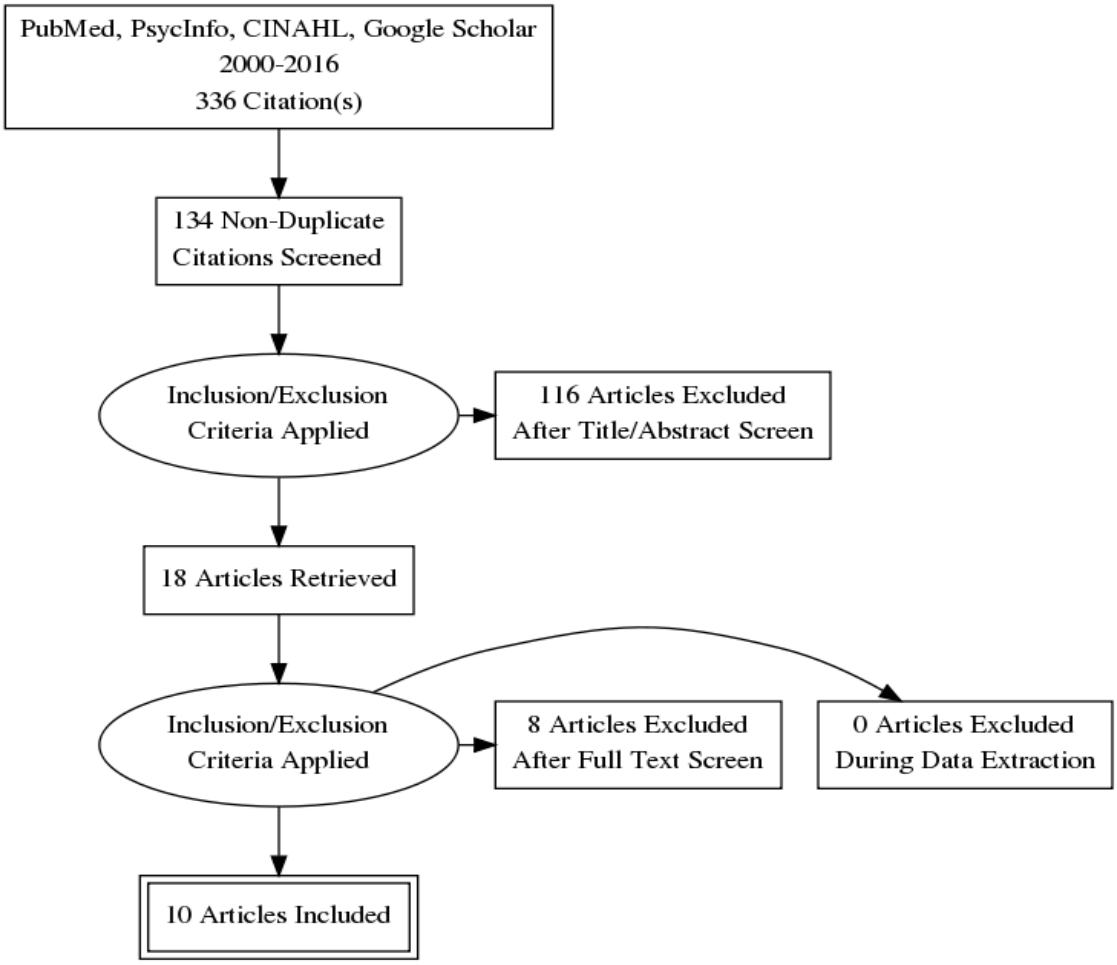
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Figure 1.1

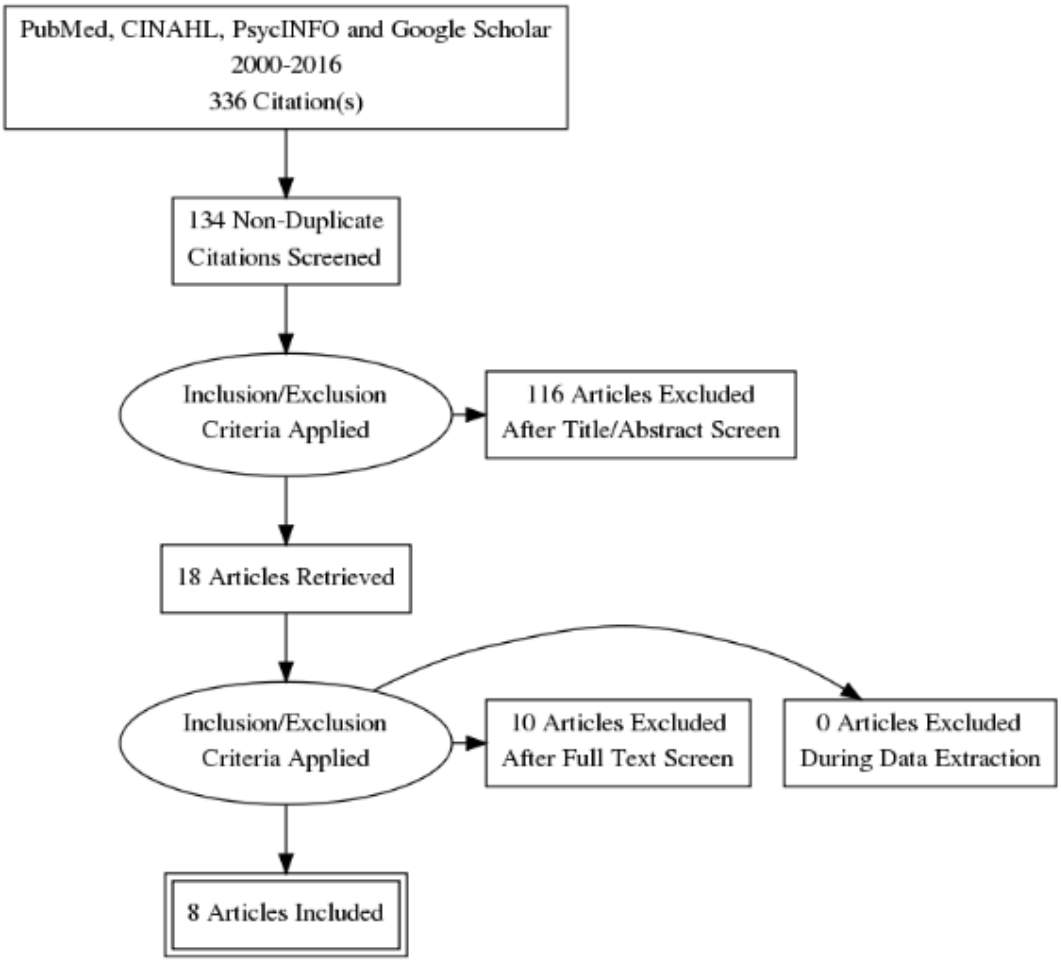
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Figure 2.1

Figure 3.1