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# Benefits of Adult Day Services for Dementia Caregivers: A Systematic Review

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Benefits of Adult Day Services for Dementia Caregivers:

A Systematic Review

by

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MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
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St. Paul, Minnesota  
in Partial fulfillment of the Requirements for the Degree of  
Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University - University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

## Abstract

Dementia is a growing problem in the world; not only for those with the disease, but also for their families, friends, and caregivers. Adult day services can provide much needed respite for caregivers of people with dementia. This systematic review was devised to answer the question: what are the benefits of and how effective is adult day services as a form of respite for caregivers of persons with dementia? Searches for peer reviewed articles in SocINDEX, Social Work Abstracts, PsycINFO, and PubMed were performed using the terms “adult day services” or “adult day care” or “adult day health care” AND “caregiver respite” or “respite care” or “caregiver” or “carer” AND “dementia” or “Alzheimer’s disease”. After inclusion and exclusion criteria were applied, 10 articles remained and were reviewed. Seven themes emerged from the literature after review, and these included: 1) role overload, 2) care related stressors, 3) mood, 4) health, 5) relationships, 6) cost, and 7) symptoms management. These themes pointed to the benefits that caregivers gain from using adult day services as respite and suggest that adult day services can be an effective form of respite. Future research on this topic should include research regarding the impacts adult day services as respite can have on caregiver depression, economic status/stress, physical health, and caregiver’s use of respite time. Adult day service agencies can use the findings from this research in order to provide services that can benefit caregivers the most.

*Keywords:* dementia, caregiver, adult day services, respite

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## **Introduction**

In 2015 the population in the United States of those 65 years and older was 47,830,000; by 2020 the population of those 65 years and older is estimated to be at 56,441,000 (Bureau of Census, 2016). Of those Americans who are 65 and older, over five million of them are living with Alzheimer's disease (Alzheimer's Association, 2016). Individuals with Alzheimer's disease or dementia often need a caregiver, and this frequently falls to family members. The over 15 million caregivers that are caring for those with Alzheimer's disease are estimated to have provided 18.1 billion hours of care, all of which is unpaid (Alzheimer's Association, 2016). Caregivers who are caring for a family member can spend over \$5,000 a year providing for their family member's needs (Alzheimer's Association, 2016). Not only do caregivers experience a financial burden while caring for a person with Alzheimer's disease, but they also often experience physical, emotional, and social strain. Stress and depression are commonly rated as high among caregivers; and many caregivers have concerns about their own health and their ability to maintain their health (Alzheimer's Association, 2016).

## **Caregivers**

A caregiver is someone who provides care for another, often children, elderly, or chronically ill. Caregivers can be professionals and can provide services for pay; they can also provide unpaid care, often for a family member. For the purposes of this study, a caregiver will be defined as a person providing unpaid care for someone with Alzheimer's disease or dementia. For the most part, this population of caregivers will include family members, although the relationship between the person with the disease and the caregiver may vary. A recent report on caregivers found that 42% care for a parent, 12% care for a spouse or partner, 5% an adult child, and 3% a sibling (AARP Public Policy Institute & National Alliance for Caregiving, 2015). In

that same report, it is stated that almost half of the caregivers who were asked reported having no choice in becoming a caregiver (AARP Public Policy Institute & National Alliance for Caregiving, 2015). A sense of familial obligation may have some impact on how and why people become caregivers. The relationship between a caregiver and the person with dementia can be complex and may have an impact on the gains or burdens that caregivers experience.

### **Adult Day Services**

Adult day services are intended to provide community-based care for older adults, while also providing respite for caregivers. Adult day services can consist of therapeutic services, such as support groups, therapeutic activities, one on one therapy, family therapy and support, etc.; social services, including activities, events, meals, snacks, coffee time, etc.; and health services, such as nursing care, physical therapy, speech therapy, etc. Some adult day services are locked facilities to provide safe care for those who may wander due to dementia, and some are not. Adult day services might specialize in caring for people with dementia; however, some may not be equipped to provide the care needed for clients with dementia.

For the purpose of this study, respite will be defined as a period of rest from a demanding situation. The behaviors that can accompany Alzheimer's disease and dementia can make caregiving a very stressful task, and for many caregivers it is a 24-hour job. Adult day services can give a caregiver the opportunity for respite during the day. National Adult Day Services Association (2016) states that "adult day services are leaders in community based care for individuals with Alzheimer's disease and other dementias," generally due to the secure environment and cognitively stimulating programs they provide.

### **Caregiver Burden**

Although Alzheimer's disease and dementia generally affect older populations,

caregivers are not limited to a certain age group or population and neither are the strains that come with caregiving for this group. The unpaid care that most caregivers provide is estimated to be around \$221.3 billion nationally (Alzheimer's Association, 2016). The financial strain can be huge for some families, but the cost of alternatives is even higher. The average cost in 2012 for assisted living was approximately \$120/day (\$3,550/month), \$248/day for a private room in a nursing home, and a daily rate of \$70 for adult day services (MetLife, 2013). Another MetLife (2011) survey found that women who are caregiving for a parent lost an average of \$185,049 in potential wages due to reduction in hours worked and \$274,044 due to leaving the work force; for men those numbers were \$164,857 and \$233,716 respectively. In total, almost \$3 trillion is lost for the over 9 million people over the age of 50 who are caregiving for a parent (MetLife Mature Market Institute, National Alliance for Caregiving, & Center for Long Term Care Research and Policy at New York Medical College, 2011). The Alzheimer's Association (2016) states that those who are contributing to caregiving lose over \$15,000 in annual income due to caregiving responsibilities; this is problematic due to the fact that 41% of those caregivers have a household income that is \$50,000 or less.

Beyond the financial burden, many caregivers also suffer strains on their physical and emotional health. Due to the responsibilities and time commitments that many caregivers face, approximately 1 in 5 caregivers will go to fewer of their own doctors visits, and 74% of caregivers report concerns about maintaining their health while being a caregiver (Alzheimer's Association, 2016). Around 40% of caregivers experience depression and over half of caregivers report high or very high levels of emotional stress from caring for a loved one with Alzheimer's or dementia (Alzheimer's Association, 2016). Understandably, as the amount of hours of care a person provides rises, the more emotional stress they are likely to experience (AARP Public



Policy Institute & National Alliance for Caregiving, 2015). The physical and emotional burden that some caregivers experience can in turn impact their ability to care for their loved one. Not only will this negatively impact the person with dementia or Alzheimer's, but it can also cause an increase in caregiving related stress for the caregiver. Caregiving often becomes central to a caregiver's life and identity and if the caregiver's own physical or emotional health declines they may no longer be able to maintain the caregiving role, which can further damage the caregiver's health.

### **Respite Care**

The literature on respite care for caregivers is broad and deep, looking in many directions and considering the many ways in which caregivers can receive respite, as well as pointing to how little respite care is actually used regardless of how it is being provided. Many studies look at respite as a whole, and not directly at adult day services as a form of respite. One study that looked at caregivers who were unemployed versus those who were employed found that unemployed caregivers who received respite from adult day services wished to use their respite time to complete personally important activities, whereas caregivers who are employed generally used their respite time to work and could benefit from more respite time to complete fulfilling activities (Utz, Lund, Caserta, & Wright, 2012). The Utz, et.al. study echoes a finding by Gottlieb and Johnson (2000) which found that respite care can be beneficial, but caregivers are not accessing services early enough in the caregiving process. Once they do access respite services, they do not use them to the extent that they could and to the most personal benefit. Both these studies point to the fact that respite services are used too infrequently by caregivers and are not used to the benefit of the caregiver.

The reasons that a caregiver may seek out respite services vary just as much as the ways

in which respite can be provided. A study regarding the reasons that caregivers do or do not use adult day services found that caregivers who use adult day services consider their need for respite as valid and recognize that the respite will help them provide better care for a longer period of time (Phillipson & Jones, 2012). Phillipson and Jones (2012) also found that caregivers who do not use adult day services have the mindset that if they were to need respite that it would be a sign of failure or their inability to cope with their loved ones' needs. Those who work with caregivers should consider these different beliefs and mindsets as they suggest adult day services as an option for caregivers.

### **Research Question**

This study will be an authoritative review of the current literature surrounding adult day care as respite; this is important because there are currently no systematic reviews covering this topic. Caregiving can cause great amounts of strain on caregivers and their families. It is important to consider how best to support caregivers as they shoulder the financial, physical, and emotional burden of caring for a person with Alzheimer's or dementia. Using information gathered through research, staff of adult day services may be able to provide better services to caregivers. Although the person with Alzheimer's or dementia is considered the client (the person to/for whom services can be billed), their wellbeing is often related to the wellbeing of their caregiver. By considering the impact that respite care can have on caregivers, agencies will still be providing services that will benefit their clients. The wellbeing of the caregiver should be as much of a focus for adult day services as the wellbeing of the clients who are directly served. This study conducted a systematic review of the literature to answer the question: what are the benefits of and how effective is adult day services as a form of respite for caregivers of persons with dementia?

## **Methods**

### **Research Purpose**

The purpose of this systematic review was to explore and better understand the benefits of using adult day services as a form of respite for those caregiving for persons with dementia. For the purpose of this study, adult day services as a form of respite refers to therapeutic, social, and health related services provided at an agency for adults with dementia, which provides time for the caregiver away from actively caregiving while the person with dementia still receives care. Homecare, nursing homes, assisted living, and other forms of respite care were not considered for this study as this study is intended to focus on the use of agencies that provide care and services outside of the home. Adult day services that do not provide care for people with dementia were also not considered for this study. For the purpose of this study, a caregiver refers to a family member or friend who is providing unpaid care to a person with dementia. Both caregiving in the home and unpaid caregiving from outside the home (i.e. an adult child caring for a parent aging in their own home, a friend caregiving while still living separately from the person with dementia) were considered in this study. Paid caregiving was not considered as a part of this study because paid caregiving is a form of respite in itself for families. All forms and stages of dementia were considered for this study.

### **Type of Studies**

In order to understand the benefits of using adult day service as respite for caregivers who are caring for persons with dementia, this study used peer-reviewed, empirically based, quantitative and qualitative studies. This study focused on the benefits for and experience of the caregivers, so the experiences of persons with dementia and practitioners were not included.

## **Search Strategy**

An initial search of academic journals including SocINDEX, Social Work Abstracts, PsycINFO, and PubMed found no systematic reviews which address the benefits of adult day services as a form of respite for caregivers of persons with dementia. A search for sensitivity and specificity were performed in order to gain a better understanding of the scope of available literature on the topic. A sensitivity search allows for a wide scope to allow for an understanding of the breadth of literature available. This type of search often collects articles which are not relevant to the research question. A search for specificity narrows the scope and increases the likelihood of finding relevant articles; however, this type of search has the possibility of missing relevant articles due to more constricting search parameters. Using both a search for sensitivity and specificity allows the researcher to understand the available research and consider which search terms should be included or excluded in order to narrow down the literature being used. Searches for both sensitivity and specificity were performed for this study.

For the sensitivity search the terms used in the search were “adult day care” which yielded 1,849 results on SocINDEX, “caregiver respite” with 257 results, and “dementia respite” with 88 results. For the specificity search on SocINDEX the terms searched were “(adult day care) AND (caregiver respite) AND (dementia)”, which yielded 17 results. It was determined the study was feasible.

## **Review Protocol**

Peer-reviewed, full text articles were considered for this review. Research performed in English speaking countries including the United States were considered for this review. The literature was found using SocINDEX, Social Work Abstracts, PsycINFO, and PubMed. The

searches and collection were performed during October of 2016. These parameters were put in place as means to address the specific parameters of this research.

### **Inclusion Criteria**

Searches in SocINDEX, Social Work Abstracts, PsycINFO, and PubMed were performed using the terms “adult day services” or “adult day care” or “adult day health care” AND “caregiver respite” or “respite care” or “caregiver” or “carer” AND “dementia” or “Alzheimer’s disease”. SocINDEX returned 24 results, Social Work Abstracts returned 21 results, PsycINFO returned 45 results, and PubMed returned 307 results which included the specified terms.

The intent of this research was to consider how adult day care functions as a form of respite for caregivers of persons with dementia. Articles that were included involved primary caregivers of persons with dementia who used adult day care services. Caregivers could include family or kin relationships, as well as friend relationships, as long as the person was considered the primary caregiver of the person with dementia. Similarly, caregivers were included whether they lived with the person they were caring for or if that person lived apart from the caregiver. However, persons living in nursing homes, long term care, or other institutions were not considered.

### **Exclusion Criteria**

After eliminating results that showed up in multiple databases, only 12 of the 397 results met inclusion criteria. Results that were excluded from review included: books or non-peer reviewed articles; articles in languages other than English; research that did not include caregivers, adult day services, or dementia; and articles that did not focus on the benefits of adult day services. Inclusions and exclusions were determined based first on the title of the article,

Table 1: Included Articles

Title	Author(s)	Caregiver Benefits
Adult Day Programs for Elderly Who Are Mentally Impaired and the Measurement of Caregiver Satisfaction	Dziegielewski, S. F., & Ricks, J. L. (2001)	-Improved relationship status
Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers	Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M. P., Townsend, A., & Greene, R. (2002)	-Reduced role overload, worry, and strain -Better psychological well-being -Better symptom management
Respite for Dementia Caregivers: The Effects of Adult Day Service Use on Caregiving Hours and Care Demands	Gaugler, J. E., Jarrott, S. E., Zarit, S. H., Stephens, M. P., Townsend, A., & Greene, R. (2003)	-Better symptom management
Evaluating Community-Based Programs for Dementia Caregivers: The Cost Implications of Adult Day Services	Gaugler, J. E., Zarit, S. H., Townsend, A., Stephens, M. P., & Greene, R. (2003)	-Reduced role overload -Improvement in depressive symptoms -Better symptom management
Medical and Social Adult Day Service Programs: A Comparison of Characteristics, Dementia Clients, and their Family Caregivers	Leitsch, S. A., Zarit, S. H., Townsend, A., & Greene, R. (2001)	-Reduced role overload and worry -Improvements in depressive symptoms -Less anger -Lower costs
Health Trajectories of Family Caregivers: Associations With Care Transitions and Adult Day Service Use	Liu, Y., Kim, K., & Zarit, S. H. (2014)	-Reduced role overload -Improvements in depressive symptoms -Better health perceptions -Less pain
Day Care for older dementia patients: Favorable effects on behavioral and psychological symptoms and caregiver stress	Mossello, E., Caleri, V., Razzi, E., Bari, M. D., Cantini, C., Tonon, E., . . . Masotti, G. (2008)	-Reduced care burden -Improvements in depressive symptoms
Measuring the Effectiveness of Adult Day Care as a Facility to Support Family Caregivers of Dementia Patients	Schacke, C., & Zank, S. R. (2006)	-Improved relationship status -Lower care-related stressors
The Effects of Adult Day Services on Family Caregivers' Daily Stress, Affect, and Health: Outcomes From the Daily Stress and Health (DaSH) Study	Zarit, S. H., Kim, K., Femia, E. E., Almeida, D. M., & Klein, L. C. (2013)	-Lower care-related stressors
Effects of Adult Day Care on Daily Stress of Caregivers: A Within-Person Approach	Zarit, S. H., Kim, K., Femia, E. E., Almeida, D. M., Savla, J., & Molenaar, P. C. (2011)	-Lower care-related stressors
Stress Reduction for Family Caregivers: Effects of Adult Day Care Use	Zarit, S. H., Stephens, M. A., Townsend, A., & Greene, R. (1998).	-Reduced role overload and worry -Lower care-related stressors -Improvements in depressive symptoms -Less anger -Better psychological well-being
Daily Stressors and Adult Day Service Use by Family Caregivers: Effects on Depressive Symptoms, Positive Mood, and DHEA-S	Zarit, S. H., Whetzel, C. A., Kim, K., Femia, E. E., Almeida, D. M., Rovine, M. J., & Klein, L. C. (2014)	-Lower care-related stressors -Increased DHEA-S levels -Better psychological well-being

then on the abstract of the article. Of the 25 articles that remained after excluding based on title and abstract, 13 more were excluded based on content not relating to inclusion criteria. After these exclusions were made 12 studies remained that were included based on containing relevant and usable information. See Table 1 for a list of the articles included in this review.

### **Findings**

The purpose of this systematic review was to consider: what are the benefits of and how effective is adult day services as a form of respite for caregivers of persons with dementia? By using the databases SocINDEX, Social Work Abstracts, PsycINFO, and PubMed, and by means of the inclusion and exclusion criteria mentioned previously, 12 peer-reviewed articles were reviewed. A majority of the articles focused on the primary caregiver (n=11), with only one of them studying caregivers who provide a majority of the care but were not specified as primary caregivers. Four (34%) of the articles did not specify whether the caregiver had to be related to the person with dementia. One (8%) article stated that the caregiver was caring for a loved one; however, this does not specifically indicate they are related to the person with dementia. Seven (58%) of the studies specified that the caregiver must be family or relative to the person with dementia.

All the articles included specifications regarding when a person was enrolled in adult day services in comparison to when the study began. Thirty-four percent (n=4) of the articles included persons with dementia who were already enrolled in adult day services. Two of the four articles that included those who were already enrolled in adult day services stipulated that they must be using those services at least two days a week. The other two articles did not specify how frequently the services had to have been used. Sixty-six percent (n=8) of the articles included persons with dementia who were not currently using adult day services. Four of those articles

only included persons with dementia who had never used adult day services in the past, three included those who had not been enrolled in adult day services in the prior three months, and one included those who had not been enrolled in adult day services in the previous year.

### **Thematic Analysis**

After the literature was analyzed, seven themes developed regarding the benefits of adult day services as a form of respite for caregivers who care for persons with dementia. These themes include: 1) role overload, 2) care related stressors, 3) mood, 4) health, 5) relationships, 6) cost, and 7) symptoms management.

**Role overload.** The literature showed that one of the largest benefits of adult day service use by caregivers of persons with dementia was the perceived reduction of role overload (Gaugler, et al., 2002; Gaugler, Zarit, Townsend, Stephens, & Greene, 2003; Leitsch, Zarit, Townsend, & Greene, 2001; Zarit, Stephens, Townsend, & Greene, 1998). Role overload itself is not necessarily detrimental, but role overload can cause negative outcomes. One study found that the reduction in role overload can be attributed to decreased amount of time caregivers are spending dealing with memory problems of the person with dementia (Gaugler, et al., 2002). Some of this was due to the use of adult day services and the caregivers then having fewer negative appraisals, which are negative experiences the caregiver has in relation to the person with dementia; these experiences might include worry, stress, exhaustion, and feeling like they are trapped in their care role (Gaugler, et al., 2002). The Stress Process Model was supported by Gaugler, et. al. in that as a person with dementia progresses further in the disease, their caregiver will experience more stressors; so, if the caregiver is experiencing fewer stressors then they will feel less role overload (2002). Another study found that consistent and long-term use of adult day services allowed them to become a more effective form of respite, and the negative



outcomes associated with role overload were reduced over time (Gaugler, et al., 2003b). One way in which these studies are showing that adult day services can positively impact the effects of role overload is by reducing the number of hours that a caregiver spends in that role. If a caregiver does not have to spend as many hours a day in the role of caregiver, then when they do have to fulfill their duties in that role they may not be as overwhelmed or overloaded. One study showed that adult day services allow caregivers to assess primary stressors differently, which in turn allows them to feel less role overload (Zarit, et al., 1998). Essentially, when a caregiver experiences stress, if they have the benefit of adult day services as respite, they are better able to manage the stressor and not be overwhelmed. Role overload can be managed by decreasing the amount of time someone has to spend in that role, especially when it is a high stress role, and adult day services offer that to caregivers of people with dementia.

**Care related stressors.** Another benefit found in the research was that adult day service use by caregivers helped to lower care-related stressors in that caregiver's life (Zarit, et al., 2014; Zarit, et al., 2011; Zarit, et al., 2013; Schacke & Zank, 2006; Zarit, et al., 1998). One study found that these stressors were lower specifically on days that adult day services were used (Zarit, et al., 2014). Another study found that on days that adult day services were used, caregivers were exposed to less stress; thus, they assessed their stress levels as lower (Zarit, et al., 2011).

Caregivers who seek out adult day services for respite at the appropriate time (i.e. do not wait until they are overstressed) and use the appropriate amount of respite might be shielded from some of the negative effects that chronic stress can cause (Zarit, et al., 2011). Adult day services impact how caregivers appraise their stress, which in turn lowered caregiver worry, strain, and feelings of role overload (Zarit, et al., 1998). One study found that adult day services

decreased care burden, which is stress related to the amount of time one spends caring and the limitations that causes in the caregiver's life (Mossello, et al., 2008).

**Mood.** Changes in mood were another impact that adult day services had on caregivers who used it as a form of respite. Decreased depressive symptoms were noted in many studies, although some were noted to be fairly minor improvements (Mossello, et al., 2008; Gaugler, et al., 2003b; Liu, Kim, & Zarit, 2014; Leitsch, et al., 2001; Zarit, et al., 1998). One study that found minor changes, which were not statistically significant, noted that depressive symptoms in caregivers were often not due to their status as a caregiver (Mossello, et al., 2008). Because of this, spending less time in the role of caregiver may not positively impact depressive symptoms. Adult day service use allowed caregivers to spend time on activities they enjoy, which in turn has a positive impact on their emotional and psychological wellbeing (Gaugler, et al., 2003b). Adult day service users had significantly lower levels of depression than caregivers who did not use adult day services, which may be related to the amount of time a caregiver has available to spend on enjoyable activities (Gaugler, et al., 2003b). Lower levels of depression were not the only mood-related impact that adult day services had for caregivers. Anger and worry were also indicated to be lower in caregivers who use adult day services as a form of respite (Leitsch, et al., 2001; Zarit, et al., 1998). Overall emotional and psychological wellbeing were better for caregivers who use adult day (Gaugler, et al., 2002; Zarit, et al., 1998). Adult day services as a form a respite could be beneficial in reducing emotional and psychological distress (Gaugler, et al., 2002). This reduction in distress could have a positive impact on overall wellbeing. Adult day service use was also found to have a significant relationship to greater average positive mood for caregivers (Zarit, et al., 2014).

**Health.** Caregiver health was another aspect impacted by use of adult day services as respite. One study found that use of adult day service was associated with better perceptions of their own health by caregivers (Liu, Kim, & Zarit, 2014;). That same study also noted that caregivers who use adult day services reported that they had less pain over time; and less pain was also found to be associated with lower caregiver burden and role overload (Liu, Kim, & Zarit, 2014;). Another study focused on dehydroepiandrosterone-sulfate (DHEA-S) levels in saliva samples provided by caregivers, and found that following the use of adult day services the DHEA-S levels were higher for caregivers (Zarit, et al., 2014). Lower DHEA-S levels can be an indicator of chronic stress, which can put someone at greater risk for illness (Zarit, et al., 2014). The findings that showed higher DHEA-S levels on the days after adult day service use indicated that adult day service provides time for the caregiver to recover from exposure to stress, as well as to potentially respond in a protective manner to future stressors (Zarit, et al., 2014). Adult day service use allows caregivers to be less reactive to challenges and stress, which in turn could be beneficial for health in the long-term (Zarit, et al., 2013). Overall, the literature appears to support the concept that caregivers' physical health can benefit from adult day services as a form of respite just as much as the mental and emotional health of the caregiver.

**Relationships.** The relationships between caregivers and others in their lives seem to benefit from adult day services as respite as well. Overall, adult day services as respite had a positive impact on relationships (Dziegielewski & Ricks, 2001; Schacke & Zank, 2006). Adult day services allow caregivers to feel more rested, feel relief, and do more things they enjoy, which all had an association with the caregiver feeling that their relationships were improved (Dziegielewski & Ricks, 2001). Caregivers were able to participate in more social activities and

experience less conflict in their families (Schacke & Zank, 2006). The relationship between the caregiver and the person with dementia was not included in the research as an outcome.

**Cost.** Because adult day services are provided at a cost, financial stressors and cost were involved in some of the studies. One study found that both the cost of caregiving and costs associated with employment (making changes in hours due to caregiving responsibilities, etc.) decreased for caregivers who used adult day services (Gaugler, et al., 2003b). Over time, as adult day service is continued, the cost benefits continue. The cost benefits associated with lessened role overload lessened over time; and caregivers were also able to spend more time working, which also benefited cost (Gaugler, et al., 2003b). One study that compared medical and social adult day services found that there was some financial strain associated with use of adult day services when it was a medical model, mainly because medical services cost more (Leitsch, et al., 2001). The financial strain was not enough to deter caregivers from using adult day services, especially because that same study found that adult day services benefited caregivers in many other ways (Leitsch, et al., 2001).

**Symptom management.** The amount of time caregivers spent managing the symptoms of the person with dementia was lessened with the use of adult day services (Gaugler, et al., 2002; Gaugler, et al., 2003b; Zarit, et al., 2014). In turn, this allowed caregivers to feel like they were able to complete and engage in personal responsibilities and activities (Dziegielewski & Ricks, 2001; Gaugler, et al., 2002; Zarit, et al., 2014). When caregivers did spend time caring for the person with dementia they experienced lower levels of stress, perhaps due to fewer symptoms present in the evenings following adult day service use (Zarit, et al., 2011).

Caregivers who used adult day services reported fewer behavior problems in the person they

were caring for, as well as less time spent dealing with the problem behaviors that did occur (Gaugler, et al., 2003a).

### **Discussion**

This systematic review was designed to investigate the body of literature available on adult day services as a form of respite for those caregivers who are caring for a person with dementia. Using inclusion and exclusion criteria this research was able to produce relevant and valid literature that provided a sense of what research is out there relating to this topic. What emerged from the literature included the seven themes discussed in the findings section. Most of the literature contained multiple themes, and a few touched on most, if not all, the themes. Many of the themes that were present in the literature were related to caregiver stress and the effects of that stress. This included physical, emotional, and economic effects of stress. Some of the literature suggested that the reason the caregivers were experiencing positive benefits was due to the person with dementia expending much of their energy while at the day care, so their behaviors when at home with their caregiver were fewer. Also, the behaviors that the caregivers did have to manage were not compounding on behaviors they may have had to manage through the rest of the day if the person with dementia was in the presence of their caregiver. The positive impact that adult day services as respite had on the stress of caregivers was often related to positive outcomes in other areas of the caregiver's life. Overall the literature suggests that adult day care is a beneficial form of respite for caregivers who are caring for a person with dementia.

### **Limitations of the Body of Literature**

The systematic review of the available literature not only produced many valuable findings, but it also presented the researcher with limitations and areas of inconsistency in the

body of literature regarding adult day services as a form of respite for caregivers. First, the outcomes regarding depressive symptoms in caregivers of those with dementia were not consistent. Some studies found no change in the depressive symptoms, while some found slight improvements. However, if improvements in depressive symptoms were seen they were almost never statistically significant. A few of the studies noted the challenge of measuring depressive symptoms as an outcome when conducting research around a disease that causes continued deterioration. One may predict that depressive symptoms might worsen as a caregiver watches their loved one succumb to dementia, regardless of how much respite adult day service is offering them.

A second area of inconsistency was found in regards to stress management. Most studies found that adult day services as respite allowed caregivers to better manage their own stress; however, some studies noted that, while the caregiver was experiencing less stress due to dementia symptoms and behaviors, they were experiencing stress regarding the other activities that they filled their time with (i.e. work, housework, family obligations, etc.).

Some limitations observed about the entire body of knowledge include a lack of longitudinal studies and research designs focusing on the impact that adult day services as respite has on the mood of the caregiver. It is not surprising that most of the studies surrounding dementia are not longitudinal. Dementia is a degenerative disease and it can progress quickly. When studying respite use for caregivers it could be challenging to study them longitudinally when the person they are caring for has dementia and may decline to a point where they are no longer able to live at home with their caregiver. However, that does not mean that longitudinal or experimental designs could not or should not be considered. A more controlled study could produce very valuable information regarding outcomes for caregivers, perhaps even beyond the

time of their role as a caregiver.

There is also a challenge of determining the impact that adult day services as respite has on caregiver mood. A diagnosis of dementia, and the symptoms and behaviors that come with it, have a different impact on every person who experiences it. Because of this variety, measuring a mood outcome in relation to respite could be very challenging. It is also challenging because dementia is a degenerative disease; although respite care may be benefitting the caregiver, their mood may be declining due the increased behaviors and decreased health of the person with dementia they are caring for.

### **Future Research**

The findings and limitations together present a variety of areas on which future research could focus. As noted in the previous section, experimental research would be beneficial to the body of knowledge. Considerations should be made when selecting participants in future research as well. Specifying whether caregivers are employed or unemployed might allow researchers to gather valuable information regarding the benefits of adult day services as respite. It may also be valuable to specify whether caregivers are living with the person with dementia or if they are caregiving from outside the person's home. Further specifiers regarding future participants that may add value to the research are: gender, relation to person with dementia, age, socioeconomic status, culture/ethnicity, and others. By creating more specific populations to research or compare, researchers and practitioners would be able to gain valuable insight into how best to serve caregivers.

Further research on the impact that respite may or may not have on depression in caregivers would also be beneficial. By doing more research, depression outcomes related to adult day services as respite would allow researchers to determine whether it is beneficial or not,

which is not currently the case. Also, it often seems that many other outcomes are related to depression or depressive symptoms, so understanding depression more could lead to better understanding of other outcomes measured in this research.

Another area where further research is needed would be in the cost or economic implications of using adult day services as a form of respite. Caregiving can have large economic consequences for caregivers, so understanding the costs of respite use is important. Research surrounding the cost of adult day services and the impact that has on a caregiver's economic status should be considered. Research that considers the economic benefits of adult day services as respite for caregivers would also add valuable information to the current body of literature. This type of research could have an impact on how adult day services charge for services, and how they appeal to potential clients.

The consequences of caregiving on caregivers' physical health is another area that could benefit from further research. Mental health seems to often be the focus of research, which is valid and useful. However, caregiving can also have effects on physical health, and physical health can impact caregivers' ability to continue caregiving, mental health, cost/economic status, and many other factors in their life. Research surrounding how adult day services as respite for caregivers may or may not impact physical health would add valuable information to the current body of knowledge, as well as provide valuable information for practitioners.

The current body of knowledge would also benefit from further research regarding what caregivers are doing during the respite time that adult day services provide. Not only would this provide a better understanding of what respite currently looks like for caregivers, but it would provide valuable information regarding what respite needs to look like for caregivers moving forward. By researching what caregivers do with their respite time, researchers may be able to



understand what provides the most benefit for caregivers. Researchers and practitioners could move forward with recommendations for caregivers as to how to use their respite time to gain the most benefit.

### **Implications for Policy and Practice**

The findings from this systematic review provide many implications for policy and practice in the field of adult day services and work with caregivers of people with dementia. First the findings suggest that overall adult day services are beneficial forms of respite for caregivers of people with dementia, so educating caregivers about these benefits would be best practice for social workers. Also, providing this information for those involved in policy development regarding adult day services and respite care would be important to help policy makers better understand the value of these services. It would also be valuable to educate other social workers and providers about the benefits of adult day services as a form of respite. If other providers have knowledge of the services provided and the potential benefits of those services, then they can refer clients to adult day services with knowledge of how and for whom they can be helpful.

Another implication for practice would be education of caregivers in regards to how they are using their respite time. Although there is not abundant research regarding the best ways to use respite, it is valuable to consider how one might use it. It may not be a social worker's job to tell the caregiver how to use their time, but it would be best practice to be sure a caregiver has put thought into their use of respite time and is intentional or has a plan for how the respite time can be most beneficial to them. This discussion would look different for every caregiver, and it is important that it be tailored to that caregiver and their lifestyle. Employed caregivers may need to be reminded that if they only use their respite time to go to work then they may not have

any time for themselves throughout the day. For a retired caregiver it may be valuable to consider involving other people in their respite time so they are socializing outside of their caregiver role. Whatever the conversation looks like, it is valuable for social workers to have them with caregivers using adult day services as respite.

Another implication for both policy and practice is expanding the services provided by adult day services. Although respite and care for the person with dementia are the foremost services provided by adult day services, it may be very valuable to include more services aimed at assisting caregivers. Some additional services that may be beneficial may include: mental health services for the caregiver, support groups, case management and referral services, etc. While caregivers may be willing to seek these services, they may not have the time or resources to research them outside of their respite time provided by adult day services. If the services aimed at caregivers were included in the adult day service agency, then more caregivers may utilize and benefit from them.

Finally, addressing the cost and accessibility of adult day services will be very important. Dementia does not discriminate, and caregivers of all socioeconomic status could benefit from the respite provided by adult day services. Respite should be accessible to anyone who needs it, and this should not come at the cost of the safety of the person with dementia. Adult day services that can provide care for people with dementia should be accessible and affordable for all caregivers. Not only does this mean considering the cost of the services, but also the hours adult day services are available. If these services are only available during the weekdays and only during business hours, then there are caregivers who cannot benefit from the respite provided by these services. Extended hours and weekend hours should be considered when adult day service agencies are examining their accessibility.

## Resources

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