This project is supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services and endorsement by the Federal Government should not be assumed.
Introduction

Respite is generally accepted to be an important component of a comprehensive strategy to support family caregivers and care recipients. However, respite-specific research to date has been limited in scope and depth, produced equivocal findings, and has been fraught with methodological flaws. Much more information is needed to document how and to what extent respite may affect the health and well-being of family caregivers and care recipients, family relationships and stability, family economic well-being, the rate and timing of out-of-home placements, and other possible health, social and economic outcomes. We also have much to learn about what types of respite family caregivers and care recipients prefer, where needs and gaps in services exist, and how to improve access to services.

ARCH in collaboration with the Administration for Community Living/Administration on Aging has convened an Expert Panel on Respite Research to develop a research agenda that will move us closer to a better understanding of the value of respite to family caregivers, care recipients, their families, and communities and how to improve service delivery and access. To guide this work and help identify where research gaps and limitations exist, a review of the literature was undertaken to provide a baseline understanding of the current body of respite research with a focus on outcomes attributable to respite. Although much has been written on the subject of planned and emergency respite (also referred to as crisis care), this initial search was narrowed to focus on caregiver, family, and economic outcomes.

ARCH last prepared an annotated bibliography in 2002. The literature review for that product identified 38 articles written between 1979 and 2001 that were published in professional, peer-reviewed journals and focused on respite and crisis care outcomes. The literature review for this updated bibliography picks up where that one left off and includes peer-reviewed journal articles published between 2001 and 2014. Studies were included if they documented outcomes of respite care for family caregivers, care recipients, families or communities, including cost-benefit studies. Relevant articles were included regardless of the sample size and research methods used (e.g., studies using qualitative and/or quantitative data collection techniques, case studies, and cross-sectional, quasi-experimental or experimental study designs). Electronic literature searches were conducted using the following data bases: CINHAL, Cochrane Library, Directory of Open Access Journals, ERIC, PsycINFO, PubMed, Scirus, SSRN eLibrary, TRIP, Wiley Online, and World Catalogue. Abstracts of over 400 articles from

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peer-reviewed journals were reviewed; 46 articles, including seven literature reviews and meta-analyses of respite evaluation studies, were selected for inclusion and summarized.

**Findings**

This review of outcome research on respite has revealed that differences in methodologies, respite definitions and targeted populations have resulted in a divergence of conclusions about the benefits of respite for certain population groups. The reviewed articles are replete with:

- Declarations of the absence of an adequate definition of respite;
- Diversity in the understanding about the intended benefits and/or outcomes of respite;
- Limitations and flaws in research methodologies used;
- Limitations in the ability to generalize or apply findings about the impact of respite on family caregivers or care recipients across ages or conditions;
- Comingling of services directed towards caregivers and care recipients, often confounding studies of outcomes for each;
- Near absence of consideration of cultural or ethnic diversity in populations studied; and
- Implicit assumptions about the value or desirability of some outcomes (e.g., placement avoidance versus deliberate and smooth transitions to institutional care).

However, many of the articles describe research that concludes that reductions in family caregiver stress and burden, improved quality of life and well-being for both caregivers and care recipients, reduced need for out-of-home placements, and reduced risk for abuse and neglect may be associated with use of a variety of models and modes of delivery of respite and/or crisis care programming. Conversely, some articles did not find similar positive associations. Some of the articles’ conclusions are not entirely favorable in terms of providing clear and compelling evidence that respite or crisis care programs achieve certain outcomes.

A few of the articles in the review that presented positive findings tended to rely on quasi-experimental research models, but even these articles are limited in terms of scope and generalizability and few employed longitudinal approaches that would provide significant additional information about the long-term effect of respite. A 2014 article by Zarit, et al, is noteworthy because it utilized a biological marker for stress in evaluating outcomes for family caregivers associated with adult day services use and is “one of the few studies demonstrating an effect of a caregiving intervention on physiologic indicators of stress.”
All of the studies included in this bibliography suggest additional research and improved research methodologies are essential to understand which aspects of respite provide positive outcomes for family caregivers and care recipients and how programs will need to be tailored to maximize these outcomes for different target populations.

Organization of Bibliography

The summaries presented include a complete citation; the study’s aim or purpose; a summary of methods; a summary of key results; key study limitations as cited by the authors; and a summary of the authors’ discussion and conclusions. Articles are grouped as follows: 1) respite targeted to children; 2) respite targeted to older adults; 3) respite targeted to adults with developmental disabilities; and 4) literature reviews/meta-analyses of respite care studies.

This review should not be viewed as exhaustive. If you are aware of an article that is not included in this bibliography, please feel free to let ARCH know. To find articles cited in this document that you would like to read in their entirety, some can be found at local public libraries or university libraries. If for some reason your library is unable to access the full article, ARCH has permission to share some, but not all, of the articles. By printing these summaries, ARCH does not endorse or promote any of the opinions expressed by the authors.

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List of Articles for ARCH Annotated Bibliography

I. Studies of the outcomes of respite targeted to children


II. Studies of the outcomes of respite targeted to older adults


III. Studies of the outcomes of respite targeted to adults with developmental disabilities


IV. Literature Reviews/Meta-analyses of Respite Care Studies


I. Studies of the outcomes of respite targeted to children


**Study Aim/Purpose:** The study’s aim was to examine the longitudinal impact of short-term inpatient respite care services on child abuse potential and family relationships among parents of children with developmental disabilities.

**Summary of Methods:** Researchers employed a quasi-experimental pre-post design comparing outcomes among a sample of 14 parents or primary caregivers of children and adolescents with developmental disabilities receiving inpatient respite care services for 4-11 days to the outcomes among a sample of 18 parents or primary caregivers whose children received short-term hospitalization (defined as 30-90 days of inpatient treatment and comprehensive medical evaluation and treatment services). Parents completed questionnaires at admission, at discharge and at 2-month follow-up on the following outcomes: 1) child abuse potential (using the Child Abuse Potential Inventory, a measure created to assess factors in parental functioning thought to contribute to physical child abuse); 2) quality of family relations (using the Family Relations Inventory); and 3) parenting stress (using the Parenting Stress Inventory-Short Form).

**Summary of Key Results:** Analysis found that neither respite care nor short-term hospitalization plus therapy resulted in significant effects on child abuse potential or family relationships, although “there were trends in the direction of reduced child abuse potential and improved family relations. Additionally, at each of the three time points, “strong interrelationships” were found between the three primary outcomes measured—child abuse potential, quality of family relations, and parenting stress.

**Study Limitations (as cited by authors):** The small sample size, the fact that the sample represents parents who were specifically seeking out certain types of services, and use of self-report measure of abuse potential were cited as study limitations. The authors also stated that their “design did not allow for the assessment of other mediating or moderating variables that could also potentially contribute to child abuse potential (e.g. social support, marital stress).”

**Authors’ Discussion/Conclusions:** “These preliminary results suggest that respite care may be insufficient to directly impact child abuse potential; however, interventions that target variables related to abuse (e.g. quality of family relations, parenting stress) might be beneficial. “ The authors suggest the need for future research with larger sample sizes and the evaluation of clinical interventions that target both family functioning and parenting stress over time (with and without respite care services). Additionally, they recommend that “future research on the impact of respite services should assess multiple types of abuse (not just physical abuse) using multiple informant sources (e.g. child welfare records).”

Study Aim/Purpose: This article summarizes research conducted using longitudinal national survey data to examine the association between receipt of respite care and academic achievement of children with disabilities.

Summary of Methods: The research was conducted using survey responses from three time points (2000-2001, 2002-2003, and 2004-2005) of the Special Education Elementary Longitudinal Study (SEELS). This longitudinal national survey, supported by the U.S. Office of Special Education Programs, is conducted with a nationally representative sample of children who were eligible to receive or receiving special education services. The authors followed the 2000-2001 survey sample of 13,176 children ages 6-12. Respite care use was measured by parent responses to a SEELS question that asked whether they received respite care for the care of their child during the past 12 months. To measure the dependent variable of academic achievement, the authors used SEELs data on child achievement in reading and math (based on a battery of questions that comprise the revised, research edition of the Woodcock Johnson III).

Summary of Key Results: Across the three time points, an average of 8.5% of the parents received respite care services over the past year and respite care receipt was associated with better academic achievement outcomes. Specifically, the authors found a statistically significant positive association (at the 0.05 level) between receiving respite care services and academic achievement across time.

Study Limitations (as cited by the authors): The use of the SEELS data set provided a nationally representative sample of children with disabilities, but precluded the examination of parental satisfaction or caregiver stress as a mediator between receipt of respite care and children’s academic achievement because no data on those parental factors are collected in the survey. The authors also note that although they did not find any distinguishing characteristics between families that did and did not receive respite care services, there may be other important family characteristics data not collected by SEELS that are related to families receiving respite care services and thus mediating factors affecting children’s academic achievement.

Authors’ Discussion/Conclusions: The study’s results “add an important component to the body of literature examining the positive effects associated with receipt of respite care for parents of children with disabilities.” The authors emphasize that linking respite care services for parents of children with disabilities to tangible beneficial child outcomes, such as academic achievement, is very important to communicate to policy makers to justify the allocation of resources for respite for this population.

**Study Aim/Purpose:** This study sought to describe the program participants and services and begin to examine the impact of crisis nurseries for children and families in Illinois.

**Summary of Methods:** This cross sectional study analyzed administrative data reported by five crisis nurseries to the Illinois Department of Human Services for State fiscal years 2001, 2002 and 2003. These data sets were based on information provided by the families at program entry and at the exit interview on the number of adults and children served, whether the children were at risk of being placed in foster care, in homeless families, or had developmental disabilities, the reasons caregivers requested crisis nursery services, reasons some parents were turned away, support services provided by the crisis nurseries and through community referrals, and information on selected outcomes as perceived by the parents. Key outcomes measured for this study were parental stress level, potential for parental child abuse and neglect, and parenting skills (measured using 3 of the 15 items from ARCH Form 5.2).

**Summary of Key Results:** In the first year of the study 79% of caregivers using crisis nursery services reported decreased stress and 90% of the caregivers in year 3 reported decreased stress after crisis nursery use. Similarly, 73% of caregivers in year 1 reporting improved parenting skills after crisis nursery use and 96% of the year 3 group reported a similar improvement. Caregiver perception of risk of maltreatment also improved from 73% of year one caregivers reporting reduced risk of maltreatment after crisis nursery use to 96% reporting the same decrease in year 3.

**Study Limitations:** The authors note that because the analysis in this study used aggregate data routinely reported by the crisis nurseries to IDHS, case level information was protected and unavailable for analysis. However, they suggest that if this kind of data were available, it would allow for a stronger analysis of the factors impacting for whom and how crisis nurseries best improve outcomes.

**Authors’ Discussion/Conclusions:** The authors discuss the many ways that “crisis nurseries in Illinois are a vital community resource in the system of care for young children and their families.” They also recommend that future evaluation research be designed that is able to use data on the characteristics of individual nursery users and link those variables to determine associations between characteristics of nursery participants, services provided, and outcomes.

**Study Aim/Purpose:** This study used aggregate administrative data from the Illinois Department of Human Services (IDHS) to assess the effects of crisis nursery services on individual caregiver service recipients.

**Summary of Methods:** This study used a cross sectional design to analyze the response of caregivers regarding the effect of crisis nursery services on parental stress, potential for abuse, and parenting skills and to identify characteristics of caregivers with the most positive outcomes. For the outcome analyses, State FY 2005 IDHS administrative data linked to crisis nurseries exit interview survey were analyzed for 638 caregivers (55% of total caregivers) served by the crisis nurseries. Independent variables used in the analyses included caregiver and child characteristics and problems that promoted initial use of the crisis nursery services. The dependent variables or parent outcomes analyzed were: 1) decrease in level of stress reported by caregivers from time of entry into crisis nursery care to the time of the exit interview post-crisis nursery care; 2) caregiver perception at exit interview that the program reduces risk of harm to their children; and 3) caregiver perception at exit interview that they “will be able to more effectively parent” their child.

**Summary of Key Results:** Descriptive analysis found that the three most common reasons for using respite were: employment/educational, self-care for parental stress, and caregiver medical needs. Among the exit survey respondents, stress reduction, potential for abuse and neglect and parenting skills were all positively affected by use of crisis nursery services. Regression analyses found that among exit survey respondents, caregivers who were single parents, had a Caucasian child, had a higher rather than lower income, had a child four years of age and older, and those who sought crisis nursery services due to a home crisis, mental health issues, or family violence were significantly more likely to report greater stress reduction compared to caregivers with other characteristics who sought crisis nursery assistance for other reasons. Consistent decreases in the potential for abuse and neglect and enhancing parenting skills were reported across all groups, thus “no statistical relationships were identified between caregiver or child attributes and these outcomes.”

**Study Limitations (as cited by authors):** One limitation noted by the authors was the differences in the socioeconomic composition of the survey respondent group and the broader population of crisis nursery users. Specifically, African Americans, caregiver households with income below $10,000, and those with lower education levels were underrepresented in the sample of survey respondents.

**Authors’ Discussion/Conclusions:** “This study found that crisis nurseries provided positive support for caregivers.”

**Study Aim/Purpose:** This study investigated the effect of crisis nursery services on the length of stay of infants and young children in foster care and other differences in placement outcomes when child welfare services were terminated.

**Summary of Methods:** Using Illinois state program data, the study authors compared foster care length and placement outcomes for children leaving foster care whose families received crisis nursery support prior to the children’s placement in foster care to these outcomes for children whose families who received foster care services but not crisis nursery services. The children in the two samples were identified by matching crisis nursery children’s data from State FY 2006 with the children’s data in the Illinois Child Abuse and Neglect Tracking System and Children and Youth Services Information System databases. After children served by both the crisis nursery program and foster care services were identified, a comparison group of children with like characteristics whose families received only foster care services was identified used as the matching group for analysis. The children were followed until their out-of-home placement was terminated or until June, 2009 whichever came first. Placement outcomes and length of stay were compared for the two groups.

**Summary of Results:** Using logistical regression analysis and controlling for such factors as child gender, ethnicity, age at placement, as well as type of abuse and country of residence, the study found that children whose families received crisis nursery services prior to foster care placement were twice as likely to be reunited with their biological families (birth or extended family members) when compared to children whose families received only foster care services. The difference in the length of stay in foster care was not statistically significant.

**Limitations of Study:** Because the study depended on data in the extant state databases, matching was only possible using the variables that were the same in both the Illinois Department of Children and Family Services databases. The authors note that other data on caregivers and child variables of interest, “such as the prenatal substance exposure of the infant, pre-maturity, substitute care, and child development data” were not available and could expand our understanding of the study results.

**Authors’ Discussion/Conclusions:** The study’s positive results indicate that families who receive crisis nursery services of any dosage may have a better chance of having their infants and young children returned to them. The authors suggest, however, that further study is needed to identify more discrete factors that explain this relationship.

**Study Aim/Purpose:** This paper examined perspectives of parents of children with disabilities on the provision of respite services through the *Aiming High for Disabled Children Short Breaks Pathfinder Programme* in England. In this program respite services are called “short breaks.”

In this program, the term is used to describe a range of services for disabled children and their families which involve the disabled child receiving support or engaging in supported activities either within or away from their family home, lasting anywhere between one hour to three weeks, and may involve just the child or in some cases group activities for the child and the family. The purpose of the study was to explore how parents talk about and use the program in the context of caring for their disabled child to better understand the need for respite and how this national program can best meet those needs.

**Summary of Methods:** The study involved in-person interviews with 17 parents using a semi-structured topic guide and the written responses of 8 parents to the open-ended question, “We want to hear from families of disabled children what role short breaks play in their lives and what are the major issues for them in using short breaks.” The interview responses and text responses were transcribed and a thematic qualitative analysis conducted.

**Summary of Key Results:** The analysis revealed that parents who took part in the program wanted and needed breaks from caring for their disabled child and the “short breaks” were crucial in helping parents with disabled children continue to provide care for them, and for others in their family. However, the analysis also documented that parents have varying perceptions about what a break from caring means. The responses indicate that parents see respite as not only restorative to help them take care of their disabled child after the break, but also to attend to the wider consequences of caring for their child. Such wider consequences mentioned included: “feeling that non-disabled children in the family are receiving less care than they should, social isolation, and the need to prepare for not being able to provide care for their child in the future.” The study also documented that parents’ need for breaks are not always being met because of misperceptions of how respite can address their needs.

**Study Limitations (as cited by the authors):** This was a qualitative exploratory study based on interviews with a convenience sampling of parents in the program and was “not intended to be statistically representative.”

**Authors’ Discussion/Conclusions:** In their discussion of the policy and programmatic implications of the study findings, the authors recommend changes to how social workers assess families’ needs for respite and tailor the respite to these needs. They suggest social workers should assess what the carer role means to individual parents and how parents perceive their need for a break.”

**Study Aim/Purpose:** This study sought to examine the effects of respite care on parental stress and the relationships between levels of respite service use, parental stress, and other parental characteristics on their children’s foster care placement and maltreatment rates.

**Summary of Methods:** Eighty-seven (87) parents completed the Parenting Stress Index (PSI) questionnaire before and after respite care use. This questionnaire (which measures parental competence and stress) was used to identify parent-child systems that are under stress and at risk for the development of dysfunctional parenting behaviors or child behavior problems. The authors assessed the PSI’s Total Stress score and three subdomain scores: Parent, Child, and Life Stress. The authors also examined rates of foster care placement and child maltreatment rates by matching the respite child client list with the state child maltreatment and foster care registries. They also examined associations between multiple parent variables and child maltreatment during enrollment in the program.

**Summary of Key Results:** Parental stress was found to be “above the high range” before and after respite use. Comparison of matched pre-respite and post-respite PSI scores found significant decreases in Total Stress scores, Parent Domain scores and Child Domain scores, after provision of care. The researchers also found that 17% of the respite parents had young children who were placed in foster care and/or had substantiated cases of maltreatment during enrollment in the program. Multiple logistic regression analysis found significant correlation between Life Stress scores and social support and the occurrence of child maltreatment during enrolment. The odds of maltreatment occurring during enrollment were also found to be highest for families receiving a medium amount (not high or low amounts) of respite services.

**Study Limitations Cited by Authors:** “In order to truly examine the intervention effect of respite care on prevention of child maltreatment and foster care placement, a control group of nonserved children with developmental disabilities would be required.”

**Authors’ Discussion/Conclusions:** The authors conclude that “respite care can be an appropriate and effective intervention to decrease stress in the parent-child relationship” for families of children with developmental disabilities. Based on the study findings (including the association between parental Life Stress and receipt of moderate levels of respite care with child maltreatment), “The investigator suggests that public health nurses can enhance their case management strategies when working with the parents of children with developmental disabilities by monitoring for caregiver burnout in addition to ensuring that the child is receiving care appropriate for his or her level of need.”

**Study Aim/Purpose:** This study seeks to describe how parents viewed the strengths and limitations of the respite component of a children’s hospice program (Canuck Place, Vancouver, British Columbia) during its first 30 months of operation.

**Summary of Methods:** This was a qualitative study involving in-person interviews with 18 parents and completed mail surveys from 65 families. The questions focused on two topic areas: parents’ perceptions of how the respite program benefitted their child and family, and prepared them for the future. Responses were coded and summarized to identify common themes.

**Summary of Results:** Overall the study found that parents of children greatly value respite care and perceive a range of benefits to the ill child, the child’s siblings, and to themselves. Parents reported that their child benefitted “a lot” or “extensively” from respite care with specific benefits including the opportunity for relaxation and enjoyment, learning, socialization, and independence. Examples of benefits noted for the parents included: a break from the routine, a sense of freedom from responsibilities and worries, time for themselves and other family members, and learning from the staff and the experience of talking to other parents with children at the hospice. Parents also reported valuing the opportunity provided to prepare for their child’s death. While the majority of the parents were satisfied with their respite care experience, some said they did not receive enough time there, families from rural areas cited time and transportation barriers to access this service, and some parents wanted more flexibility in the way the respite care was scheduled for them.

**Study Limitations (as cited by authors):** None cited

**Authors’ Discussion/Conclusions:** The authors highlight three lessons that derive from this study. First, they state that respite care is needed both on its own and as a component of a full suite of hospice services, but the availability of such respite care is “virtually nonexistent in North America.” Second, the author emphasizes the critical need for in-home respite care and recommends that its availability should be supported and mandated by public policies and programs. Finally, she calls for research to better document the need for and outcomes of children’s respite services, including “to further examine the health and psychosocial benefits of respite care for families of children with life-limiting conditions.”

**Study Aim/Purpose:** The purpose of this study was to examine the relationship between receipt of respite care and quality of marriage for couples with a child with autism spectrum disorders (ASD), with wife and husband stress and daily uplifts as potential mediating variables.

**Summary of Methods:** Data were collected from 101 married heterosexual couples of children with ASD who had received respite services. The mothers and fathers were asked to complete questionnaires separately, either via a web link or on paper. The questionnaire collected information in the following areas: 1) characteristics of the parents and children including medical diagnoses (these variables were used as control variables in the analysis); 2) husband and wives perceptions of marriage quality measured by the Revised Dyadic Adjustment Scale and the revised Experiences in Close Relationship Questionnaire scales on Anxious and Avoidant Attachment; 3) daily hassles (stressors) and uplifts, as measured by the Hassles and Uplifts Scale; and 4) number of hours of respite care received in a typical week (defined as “planned care for the children with autism to provide relieve to the permanent caregiver”).

**Summary of Results:** Number of hours of respite care was positively related to improved marital quality for both husband and wives, such that a one hour increase in weekly respite care was associated with a one-half standard deviation increase in marital quality. This relationship was significantly mediated by perceived daily stresses (hassles) and uplifts in both husbands and wives. There was also a direct association found between more respite care and increased uplifts and reduced stress; increased uplifts were associated with improved marital quality; and more stress was associated with reduced marital quality for both wives and husbands. The authors also found that having more than one child with ASD was associated with greater stress, reduced relationship quality, and daily uplifts.

**Study Limitations:** The authors note that the sample was not randomly selected. They admit that “participants were volunteers who responded to targeted invitations and may represent a particularly high level of family functioning.” Further, they note that respondents were primarily “Caucasian families from the Intermountain West area of the U.S. and thus may not generalize to other geographic areas and cultural norms.”

**Authors’ Discussion/Conclusions:** The authors emphasize their finding that “even a slight increase in the number of hours of respite care has the potential to improve marital quality.” They call for practitioners working with families who have a child with ASD and policy makers to assure these families have access to formal and informal respite care services. The authors also call for future research to assess whether increasing the number of hours of respite care for couples of children with ASD would actually improve their marital quality and whether it is the quality or the quantity of respite that influences marital quality as well as research to better understand the factors that mediate the impact of respite on marital quality.

**Study Aim/Purpose:** The study’s aim was to examine whether increasing outpatient respite and therapeutic services resulted in reduced use of psychiatric hospitalizations among children with autism spectrum disorders (ASDs)

**Summary of Methods:** The authors used a retrospective cohort study to examine the association of respite and therapeutic outpatient service use in the preceding 60 days with risk of psychiatric hospitalization for children with ASDs. The authors used Medicaid claims data from November 1, 2003 through December 31, 2004 to calculate service use. The study sample included 28,428 Medicaid-enrolled children, adolescents and young adults aged 5 through 21 who had at least two outpatient claims in May-October 2003 associated with a primary diagnosis of autistic disorder. The primary independent variable of interest was use of outpatient respite and therapeutic services and the dependent variable was psychiatric hospitalization. Child demographic characteristics (obtained from the Medicaid eligibility file) and State characteristics (obtained from Area Resource File) that may affect the observed associations were also included in the analysis. Logistic regression analysis was used to assess the association between cumulative expenditures over the past 60 days for outpatient respite and therapeutic services and hospital admission, controlling for sociodemographic and state level variables.

**Summary of key Results:** 2.4 percent of the sample experienced at least 1 hospitalization during the study year associated with a diagnosis of ASD. Analysis of the adjusted odds of hospitalization associated with respite use in the preceding 60 days found that “each $1000 increase in respite expenditures in the preceding 60 days was associated with an 8% decrease in the odds of hospitalization;” however, no association was found between the use of therapeutic outpatient services and risk of hospitalization.

**Study Limitations (as cited by authors):** The authors acknowledged that the accuracy of the ASD diagnosis in Medicaid claims is unknown and has not specifically been studied. They also noted that the process used for categorizing procedure codes has not been validated and may have affected observed associations between service use and hospitalization.

**Authors’ Discussion/Conclusions:** Explaining potential causal links between respite care use and decreased hospitalization, the authors state that “raising a child with ASD is fraught with challenges and can place considerable stress on families. Respite and home-and community-based aides may considerably reduce stress on families, leading to reduced hospitalization rates.” The authors also find that the study “results have important implications for state policy and practice,” including the expansion of Medicaid community-based options by States to ensure the availability of respite and other community-based services for children with ASD.

**Study Aim/Purpose:** The purpose of the study was to identify how “specialist short break and community support services programs” administered by Action for Children in three United Kingdom cities were perceived to meet the needs of families whose children are disabled and have severely challenging behaviors. “Family support services from these programs consist mostly of “overnight breaks in a small residential home for 2-7 days at a time.” In addition, “staff will come to the family home and accompany the child at activities within the local community while also providing advice and training to the family in managing behaviors.”

**Summary of Methods:** This is a qualitative study that collected information about 17 children with “developmental disabilities and severely challenging behaviors.” Study participants were selected randomly from the 123 children who were currently receiving services or had done so in the past 2 years. For each child, semi-structured interviews were conducted with three types of informants: a parent, the child’s key worker within the service, and the professional (usually a social worker) who referred families to the services. The interviews were recorded and transcribed and thematic content analysis was conducted to identify major themes and subthemes.

**Summary of Key Results:** The core themes to emerge in the analysis across the three local programs were: 1) complexity of family issues (including the fact that these families are often coping with more issues than having a disabled child, including caring for other special needs children, financial and housing difficulties and complexity and variation in the children’s behaviors) and perceived complexity of the package of services available from different agencies; 2) negotiations required to implement (including family ambivalence about initially using short breaks and negotiating access to the services and adjustments to the service packages); 3) the positive relationships forged between program staff and families and the children; 4) benefits to children and families (with emphasis on the fact that the children were reported to benefit most because of the complexity of the parents lives and their own needs); and 5) concerns about planning for an uncertain future (including the availability of respite once their child ages out of this service and consideration of out-of home placement for some young people).

**Study Limitations (as cited by authors):** The study was limited by the lack of a longitudinal perspective and the absence of quantitative measurement of changes in children and parents.

**Authors’ Discussion/Conclusions:** “Specialist short break services can make a vital contribution to retaining children within their families, but under some important conditions which this study has identified: notably, the management of complexity, the formation of trusted relationships and creation of tangible benefits for the family and the child.” The authors recommend that future studies build upon their findings conducting quantitative research to examine “the impact of different combinations of overnight and in-home support on parents and on children’s behaviors.”

**Study Aim/Purpose:** The study’s purpose was to examine psychosocial benefits for mothers of a one-week overnight summer camp for chronically ill children. The authors note that “this study is the first to empirically examine camp as overnight respite care for mothers of children with chronic illnesses. In addition, the large sample size and longitudinal design provide a new contribution to the empirical literature on the benefits of respite care.”

**Summary of Methods:** The study analyzed survey responses from 161 mothers whose children had chronic diseases (cancer, epilepsy, kidney disorders, or asthma). Participating mothers completed structured telephone interviews at four time points: pre-camp, during camp, immediately post-camp, and one month after camp ended. The questionnaire, developed specifically for this study, measured the following characteristics of maternal caregiving: 1) level of caregiving demands (related to medications, in-home medical care, out-of-home medical care, night-time medical care); and 2) subjective caregiver stress related to four areas of caregiving demands. Outcome measures focused on the mothers’ psychological functioning in the following areas: 1) feelings of overload (measured with 4 items developed by Pearlin); 2) depression-anxiety (measured with a subset of the Langner Screening Inventory); 3) distress related to parenting (measured with a maternal distress scale developed by Pearlin and Schooler).

**Summary of Key Results:** The level of mothers’ caregiving demands were relieved during camp, but returned to pre-camp levels once the child returned home. Despite this return to pre-camp levels of demands, mothers’ perceived overload level decreased significantly below baseline for children with all types of illnesses during camp and remained at levels lower than baseline after camp (though somewhat higher than during camp). While maternal distress and depression-anxiety levels were also reduced during camp, they were not significantly below baseline even one week after camp. Only the subgroup of mothers of children with cancer who were no longer receiving treatment when they entered the study experienced sustained decreased levels of distress after the one week of overnight camp.

**Study Limitations (as cited by authors):** The authors cited the following two study limitations: 1) measures of caregiving demands and psychological factors were all based on mothers’ self-report; and 2) the study design did not include a control group.

**Authors’ Discussion/Conclusions:** The authors suggest the following implications for practice and policies related to their findings: 1) referrals to summer camp should be incorporated into the physical and psychosocial health care of children and their families; 2) summer camps for children with chronic illnesses should be designated as an overnight respite care service to allow existing respite funding (Medicaid and other) to be used to support this model of respite; and 3) professionals who work with chronically ill children could plan and utilize respite funding to expand summer camp programs to include more frequent opportunities for overnight respite throughout the year. They also recommend that future research should continue to examine summer camps as respite care providers and measure additional outcome domains for caregivers, including the benefits of respite for all family members.

**Study Aim/Purpose:** The purpose of this study was to examine the benefits of inpatient respite services for children with developmental disabilities and their parents.

**Summary of Methods:** The study used a quasi-experimental pre-post design comparing survey responses for families who applied for and received 3-7 day inpatient services at a center for developmental disabilities in the Midwestern United States to those who applied for and received 30-day inpatient treatment at the same center and received medical, nursing, physical therapy, speech therapy, occupational therapy, recreational therapy, social work, psychology services, and family education as needed. Analyses of group differences across key demographic and illness variables found no significant differences other than length of stay. The 80 participants included in the data analysis each completed a questionnaire at three time points: admission, discharge, and 6 months after discharge. These surveys collected information on two outcomes: parents’ psychological distress (measured using the Brief Symptom Inventory) and parenting stress (measured using Parenting Stress Index). Additionally, therapy and nursing staff at the center rated the functional ability of the child at admission and discharge (using the Functional Ability Scale by Aniol and Mullions).

**Summary of Key Results:** Analyses indicate three important findings: 1) psychological distress was significantly lower at discharge and 6-month follow-up for the respite group and equal to that of the comparison group; 2) parenting stress was significantly lower at discharge, but at 6-month follow-up had returned to admission levels for both groups; and 3) both groups of children demonstrated improved functional ability from admission to discharge.

**Study Limitations (as cited by authors):** The authors note the lack of a control group as a limitation of the study design. They also point out that their data sources did not allow for measurement of mediating or indirect factors that could have contributed to the lowering of parent distress during the respite stay and after discharge. They also noted that the information collected on parent distress was limited in that it relied “solely on self-report measures of distress rather than structured interviews or observational assessments of parent-child interactions.”

**Authors’ Discussion/Conclusions:** “Taken together the results on parental outcomes suggest that brief inpatient respite care admission may well serve to diminish the more general distress that parents feel on a day to day basis and have positive benefits for the children as well.” The authors recommend that future research address the limitations of their study design and allow for documenting the differential effectiveness of respite with specific subgroups of children and families. They also expressed the need for research to assess the effect of respite services on the likelihood of maltreatment of abandonment, and the impacts of respite on overutilization of other health care services and long-term out-of-home placements.
Study Aim/Purpose: To examine parent responses and effects of a nurse-led in-home respite support service for parents of young children with complex health care needs.

Summary of Methods: This is a qualitative study involving interviews with 18 families. Parents were interviewed using semi-structured topic guides at three time points: immediately after their assessment (but before receipt of respite), 3 months later, and 12 months later. At the first interview parents were asked about their experience of the onset and/or diagnosis of health problems in their child, support available to each family, the kind of respite they required, and their expectations of the service. At the second interview, they were asked about the impact of the service on their lives and for feedback on the service. The third interview at one year reviewed parental experiences of the service over the year and asked about the extent to which the service had met their needs and contributed to family well-being. Responses were analyzed qualitatively, coding the interview transcripts and organizing the coded data into themes.

Summary of Key Results: The service is described by parents as valuable and as meeting need for some but not all of the parents. Some parents wanted a different kind of respite service, offering more flexible and immediate support, rather than the current program which provides respite through pre-booked sessions that parents request 4-6 weeks in advance. Additionally, “while the large majority of parents described moderate or significant improvements in family well-being over the study period, only 5 of those attributed respite as having had some role in this.” Furthermore, most families cited the respite service as one of a range of factors they said lead to improved well-being.

Study Limitations (as cited by authors): The authors recognize the exploratory nature of their qualitative research.

Authors’ Discussion/Conclusions: The responses “demonstrated the diverse ways in which families wished to make use of respite support, both in terms of who they saw as the beneficiaries (e.g. themselves, the family, other siblings) and in terms of what they saw the time enabling them to do.” In discussing the practice implications of their findings, the authors state that “efforts should be made to ensure that respite support is offered in a more flexible and diverse set of ways to ensure that it is targeted and tailored to each family’s need for respite.”

**Study Aim/Purpose:** This study, conducted “in a large urban area of a western state” sought to examine the outcomes associated with use of formal respite care services by kinship, foster, and adoptive caregivers of children with special needs involved in the child welfare system.

**Summary of Methods:** The study involved 71 adult kinship caregivers, adoptive, foster/adoptive and foster caregivers who completed a pre and post respite questionnaire by mail or telephone. The pre-respite instrument included “original questions and standardized measures obtained from previously published studies related to caregiving, family satisfaction, and quality of life and anticipated benefits of respite care.” The post-respite instrument included most of the questions and additional items related to perceived benefits and impact of respite care.

**Summary of Key Results:** The majority of caregivers reported reduced stress, increased time for attending to their own health needs, improved positive attitude toward their children, and significantly decreased feelings of objective burden after receiving respite care. Caregivers also reported a significant increase in “feeling at ease and supported” after participating in respite. While most caregivers reported feeling frustrated about caring for their special needs child prior to respite care, they were significantly less frustrated after receiving respite care. At the same time, the authors found that caregivers felt less equipped to care for their child after receiving respite care and there was a statistical reduction in the number of caregivers who perceived that their family members got along well.

**Study Limitations (as cited by authors):** The author notes that her study’s findings on effects were limited due to the lack of a comparison group of caregivers who did not receive respite care. They also pointed to the lack of standardized scales measuring outcomes such as caregiver depression levels and other psychiatric symptoms of the caregivers.

**Author’s Discussion/Conclusions:** The author concludes that “respite care is a viable intervention to use in future efforts at recruitment and retention of caregivers of children in substitute care.” They also suggest that the findings, such as caregivers feeling unequipped in their caregiving role, point to the need to link respite “to other services such as positive or effective parenting courses, concrete services and empowerment techniques.” They further highlight a need to “secure respite funding, provide high quality respite care, evaluate respite service empirically, and widely disseminate the evaluation findings for future enhancement and replication of respite care services” for this population.

Study Aim/Purpose: This study sought to analyze changes in costs for the Children’s Hospital of Eastern Ontario (CHEO) (a regional pediatric health care system in Canada) resulting from the provision of palliative hospice respite care for children with life-limiting illness (provided at a new 8-bed pediatric residential hospice adjacent to the hospital called Roger’s House (RH)).

Summary of Methods: The number of hospital days, emergency department visits and outpatient clinic visits and hospice use were measured for 66 children who used the hospice service. These data were obtained from a chart review evaluating the 12-month period before and after the hospice became available and the number of visits were compared before and after each child’s first visit to Roger’s House. Costs per patient day were calculated by multiplying the number of patient days and visits per month by the corresponding daily cost of the visits ($2007 daily cost for hospital and $500 for Roger’s House). The differences in costs between children using and not using hospice were calculated by comparing the health system costs for each child before and after their first visit to Roger’s House, and then calculating the mean difference in costs among all 66 children using Roger’s House.

Summary of Results: The chart review revealed that the mean number of monthly hospital inpatient days and outpatient days significantly decreased after the child’s first visit to Roger’s House, though the number of monthly emergency room visits was not affected. The key study finding was: a mean decrease in the monthly cost for CHEO is attributable to the fact that RH provides services at a significantly lower cost than the inpatient hospital facility, calculated as a $4,252 in savings per month per patient.

Study Limitations (as cited by authors): “Because the costs per inpatient day were calculated differently for each facility (the hospital based on an interprovincial rate agreement and the hospice based on average cost per patient day), the comparison is not ideal and savings may be over-or understated.” Furthermore, the authors note that: “Costs for care at home were not addressed but may be a useful addition to future studies.” They also point out that comparisons of quality of care were not included.

Authors’ Discussion/Conclusions: “This study suggests the ability of the hospice to provide comparable palliative services at a lower cost indicating that although there is increased utilization of the pediatric hospice, the opening and operation of a pediatric hospice resulted in a minimization of overall care costs.” Additionally, the authors suggest that “because a hospice has a lower patient cost per day than a hospital, the cost-minimizing approach would be to use RH at its full capacity whenever possible.”
II. Studies of the outcomes of respite targeted to older adults


**Study Aim/Purpose:** This study had two aims. The first was descriptive, to describe the characteristics of users and services received from and satisfaction with the Home Help Service (HHS), a respite program serving elders in Comunidad Valenciana in Spain. The second study aim was to measure the impact of HHS use on the burden of care among informal caregivers.

**Summary of Methods:** The authors compared caregiver burden among two randomly collected samples-- 117 users of HHS with informal caregivers and 36 non-users of HHS on the waiting list for this service who also had informal caregivers at home. Burden of informal caregiving was measured using the “Zarit Burden Interview” which comprises 22 items with five scale answers ranging from never (0) to nearly always (4) with a total score ranging from 0-88.

**Summary of Key Results:** Descriptive analysis of the characteristics of the HHS shows that it provides “low coverage and low frequency of care,” and that HHS “workers lack professional training in home care.” The survey results found that both carers of HHS users and carers of non-HHS users “experience great burden in their daily work.” Although mean burden overall was higher among carers of non-HHS users, the difference was not statistically significant. Breaking down the components of the Zarit Burden scale, both groups have a “rather strong perception of the negative repercussions of caregiving in their lives, and there is no significant differences between the two groups in this factor. Additionally, “both groups appear to report low feelings of incompetence to continue in their caregiving role,” with carers of non-HHS users having significantly higher feelings of incompetence. Neither group shows “negative feelings toward the dependent people in their care.”

**Study Limitations (as cited by the authors):** None cited.

**Authors’ Discussion/Conclusions:** The authors state that “informal caregivers of dependent elders have high burden levels that could endanger the continuity and quality of their caregiving.” However, their evaluation results found that “HHS provision does not significantly reduce” that burden. The authors conclude that improvements are needed in HHS and other respite care programs to address caregiver burden. Their recommendations include extending the type and duration of services provided and focusing on primary caregivers’ needs, with the offering of psychoeducational efforts to relieve informal caregivers emotional stress and give them skills and coping strategies.

**Study Aim/Purpose:** This study sought to measure the impact and level of hospice respite benefits used in the Hospice Caregiver Support Project, designed to provide in-home support services to unpaid, primary, at-home informal caregivers of hospice patients.

**Summary of Methods:** During the ten month project period, caregivers referred by project social workers to respite care were asked to complete a questionnaire and data analyses were primarily based on matched pre- and post-survey results completed by 23 caregivers. The survey included the Pearlin Role Overload Measure (ROM) and opportunities for open-ended responses on the benefits of and satisfaction with respite care. Questionnaires were completed immediately after their respite care was approved and again approximately 2 weeks after respite service ended. Caregivers were also asked to provide qualitative information in response to the open-ended question: “Is there anything you would like to share with us?”

**Summary of Key Results:** After receiving respite services, mean self-reported caregiver stress levels, decreased by 52%. Qualitative responses focused on the benefits of respite care and general appreciation of the services. The most common reported benefit was that respite “allowed the caregiver to get out of the house or take a break.” Other benefits cited by multiple caregivers included: “relieved stress”, “allowed the caregiver to sleep/relieved exhaustion”, and “felt safer/comforted.” Fifteen of the 23 caregivers provided mixed (positive and negative) or negative comments about the quality of the service provided.

**Study Limitations (as cited by authors):** None noted.

**Authors’ Discussion/Conclusions:** The authors closed by stating that: “These findings show that the provision of additional services through this project reduced the need for hospice patients to be removed temporarily from their home due to caregiver overload, thereby reducing the distress experienced by patients and family members.” They also called for, “more research on the cost-efficiencies of supportive services versus inpatient hospice respite benefit days.”

**Study Aim/Purpose:** The study examined the short-term (2 month) effects of adult day services (ADS) participation by individuals with dementia on their behavioral and psychological symptoms of dementia (BPSD) immediately after ADS use and on days when not using ADS.

**Summary of Methods:** A quasi-experimental design was used, comparing reports of caregivers of individuals with dementia enrolled in a NJ ADS program (N= 133) with reports from a control group of similar caregivers not using these services (N= 68). Baseline data included responses to an in-person, at-home interview of caregivers; observational logs of Daily Record of Behavior (a measure developed by the authors and adapted from the Revised Memory and Behavior Problems Checklist to document occurrence and duration of relatives’ behaviors and moods for two 24-hour periods). At one and two months after baseline, caregivers completed DRB logs for four days, including days the individuals with dementia were at ADS and days at home. Impact analysis included data on five domains: depressive symptoms, agitated behavior, night-time sleep disturbances, ADL-related behaviors, and memory issues.

**Summary of Results:** The ADS use group showed a significantly greater decline in duration of night-time sleep problems than the comparison group, although the occurrence of those problems was similar in both groups. The effects for the ADS group on duration of sleep problems were stronger on ADS use days vs. non ADS use days. At the same time, no significant cross-group differences were found for either occurrence or duration of depressive symptoms or agitated behavior. However, within-group analysis for the ADS group found that the occurrence of depressive symptoms and incidence of agitated behaviors were all significantly lower over time on ADS days compared with non-ADS days.

**Study Limitations (as cited by authors):** The authors cited study design limitations including the study’s short-term nature, and lack of reporting on specific domains or missing data from caregivers’ logs. Authors note that “attrition could have had an impact caused by differences in characteristics of participants who were missing data--who tended to be older, have older persons with dementia, and more often came from the ADS group.” The authors also point to the limitations of using a quasi-experimental design to evaluate treatment outcomes.

**Authors’ Discussion/Conclusions:** The authors discuss the importance of connecting services provided at ADS to outcomes for participants with dementia: “In the present study, the ADS participants engaged in about 30 minutes of daily physical activity and only 13% of participants took naps while at the program. This compares to 75% of participants who took naps on non-ADS days. These results suggest the need for further study to explore the extent to which targeted activities and training might improve sleep.” They also suggest that “future studies of the impact of ADS on behavioral and other dementia-related problems could adopt a more strategic approach to targeting people for interventions... People with a particular type of problem could then be matched with the right types of activities.... There may also be a need to involve caregivers in the treatment plan so that they could carry over some of these strategies to the home.”

**Study Aim/Purpose:** The objective of this study was to determine whether adult day service (ADS) use and its related reductions in primary caregiving hours would positively impact caregivers’ negative emotional appraisals (i.e. exhaustion and fatigue, feeling of being trapped in the caregiving role) and levels of psychological distress.

**Summary of Methods:** This study used a quasi-experimental design with a treatment group of caregivers of individuals with dementia who would be using adult day services (ADS) in a NJ statewide program and a control group of caregivers of individuals with dementia residing in a similar sociodemographic region (Northeastern Ohio) where ADS were not widely available. The cohort of 169 treatment caregivers and 231 comparison caregivers completed interviews at baseline and three months later and these results were included in the data analysis. In addition to collecting basic descriptive information on the caregivers at baseline, at each interview caregivers provided information for the month prior to each interview on the following topics: 1) number of hours they spent assisting and/or managing ADLs, IADLs, behavior problems and memory problems during a typical day; 2) caregivers’ perceptions of their role captivity (being trapped in care responsibilities), role overload, level of worry and strain and psychological well-being; 3) care demands measured by the occurrence of behavioral problems, problems with memory loss for their relative with dementia; 4) whether their relative with dementia required their assistance to complete ADLs and IADLs; and 5) the number of hours of assistance provided by other family members or paid help. The regression analysis to test associations between ADS use and hours of caregiving and caregiver stress controlled for multiple variables including: sociodemographic characteristics of the caregivers and care recipients; frequency and severity of problematic behaviors, ADL/IADL dependencies, and cognitive impairment of the individual with dementia; and the amount of assistance provided by other family members or paid help.

**Summary of Key Results:** The primary statistically significant finding was that caregivers using ADS who reported decreases in hours spent helping with memory problems were more likely to report decreases in “role overload” than the comparison group of non-ADS users. An opposite interaction effect occurred for change in worry and strain among a subgroup of non-ADS users: non-ADS users who reported greater decreases in their relatives ADL dependencies over the three-month study period were more likely to report decreases in worry than were ADS users.

**Study Limitations (as cited by authors):** Since this was a quasi-experimental study design, the authors state that “Unknown variations (in the characteristics of the treatment and control groups) at baseline may have influenced the robustness of the results.”... “Also relying on caregivers’ self-reported time estimates in the month prior to each interview may have increased the potential for recall error.”

**Authors’ Discussion/Conclusions:** The authors suggest that the following as explanation for the study’s positive findings of associations between ADS use and reported “role overload.” By relinquishing care
demands for several hours a week, adult day service users could have had more time to complete other necessary demands efficiently when compared to caregivers whose relatives remained at home, thus leading to decreased feelings of exhaustion. Alternatively, some adult day programs may have provided services that helped reduce more severe disorientation and/or repetitious questioning on the part of clients. By addressing the memory problems of clients, adult day services may have offered caregivers the relief necessary to reduce feelings of exhaustion and fatigue.

**Study Aim/Purpose:** The study’s purpose was to examine the short and long-term effects of the Adult Day Service Plus (ADS Plus) program, which integrates care management within adult day center services with the goal of “helping family caregivers develop problem-solving and coping skills, improve social and instrumental support, and enhance perceived competence in managing the difficult behaviors of their impaired elder.”

**Summary of Methods:** The study used a quasi-experimental design. The intervention group was comprised of caregivers enrolled in two centers’ ADS Plus programs and the control group was comprised of caregivers enrolled at a center where their elder relatives received only the usual ADS. 129 caregivers were enrolled in the study and interviewed by the program social worker at baseline, 106 were available at the 3 month follow-up assessment, 74 were available at the 6-month assessment, and 58 were available at the final 12-month assessment. Trained interviewers, who were not familiar with the study hypotheses conducted in-person or telephone interviews at 3, 6 and 12-month follow-ups. The primary outcomes assessed during these interviews were: 1) caregiver depression (measured using the 10-item version of the Center for Epidemiologic studies-Depression scale); 2) burden (measured using 123 items from the Zarit Burden Interview); 3) memory and problem behaviors and self-efficacy in managing these behaviors (measured using the Zarit and Zarit 24-item Memory and Problem Behaviors scale); 4) perceived degree of change in well being (measured using the 13-item Perceived Change Index); 5) time for healthy behaviors (measured using 6 items from the NIH Resources for Enhancing Alzheimer’s Caregivers’ Health initiative); 6) number of days using ADS; and 7) nursing home placement during the study period.

**Summary of Key Results:** At 3-month follow-up, ADS Plus participants reported less depression, improved confidence managing behaviors, and enhanced well-being compared to the basic ADS group. Long term effects analyses (6 and 12months) showed that, compared with controls, ADS Plus participants continued to report less depression and enhanced confidence managing behaviors. Additionally, mean use of ADS services was 37 days longer for ADS Plus participants than controls and ADS Plus users had fewer nursing home placements than those who received basic ADS.

**Study Limitations (as cited by authors):** The authors did adjust for differences between the groups in all analyses. However, they were unable to control for potential confounders such as quality and number of staff-family interactions that may have differed across sites. They also note that the attrition rate was substantially different between groups, which may have affected the analyses of long-term effects.

**Authors’ Discussion/Conclusions:** “The study clearly demonstrates the potential benefits of targeting both the older person using ADS as well as the family caregiver in assessment and treatment.” This approach “may also serve as a model for integrating caregiver assessment and treatment into other long term care service programs that traditionally target only the impaired adult.” Furthermore, “although an important objective of “ADS is to help families delay nursing home placement, this study suggests that
without systematically targeting the concerns of family caregivers, this objective may not be fully achieved.” The authors suggest that further research is needed to substantiate the findings of this study to other centers, examine the components of the intervention to determine which components contribute to improved caregiver outcomes, and to conduct analyses of costs and cost savings.

**Study Aim/Purpose:** To describe the Older Carers Program in Western Australia administered by the Australian Red Cross and whether it met its stated objectives and carried out its intended activities. This 22-month old program at the time of the research was designed to provide help for older carers of adults with disabilities through home visits, development of integrated care plans, encouragement of regular planned respite, referrals to needed service providers, and access to a database of volunteers.

**Summary of Methods:** This was largely a process evaluation, with an audit of the program database designed to describe program participants and determine whether services provided met the program’s objectives. In-depth semi-structured telephone interviews with 62 older carers provided input on participant satisfaction and qualitative descriptions of their needs. Questionnaires completed by the four Program Coordinators provided input on program implementation successes and recommendations.

**Summary of Key Results:** Older carers reported that the most useful aspects of the program for them were: (1) visit/support from the program staff, (2) respite, and (3) information giving. When asked to provide feedback on the quality of the program and satisfaction, the overwhelming majority of older carers provided high positive rating. The overwhelming majority also said the program had a positive impact on their role as a caregiver. However, when carers living in rural areas were compared to those living in metropolitan areas, the authors found differences in satisfaction with services, access to respite services, and perceptions of needs being met. Specifically, rural older carers reported lower satisfaction with the program, lack of respite services, staffing problems, and only 28% of carers in rural areas said their needs had been met, compared to 80% of the metropolitan carers.

**Study Limitations (as cited by authors):** The authors note that their research was based on a small program, but suggest that the findings can apply to other population groups, particularly Western nations with aging populations and limited resources to assist older carers.

**Authors’ Discussion/Conclusions:** The authors highlight the need for policy makers and program service agencies to address the unique position which older carers find themselves compared to other carers in the population. They suggest two issues as most prominent and important to address for this group: 1) the lack of suitable accommodation in long-term and respite services for the care recipients; and 2) the fact that most of the older carers have been in a caring role for decades. Although “planning for the future needs of the care recipient is fundamental,” many “could not face this prospect as it involved their loved one living alone in an institution.”

**Study Aim/Purpose:** This study sought to evaluate the impact of two weeks of institutional respite care provided in four community hospital units in East Midlands, United Kingdom on sleep patterns of patients with dementia who normally live at home.

**Summary of Methods:** The authors describe their study design as “prospective case series.” Baseline measurements of sleep outcomes for 33 dyads of caregivers and patients were taken for 2 weeks prior to receipt of the institutional care, during 2 weeks of respite, and two weeks at follow-up using the Actiwatch system. Caregivers were also provided questionnaires at baseline, daily sleep diaries, and completed weekly Epworth Sleepiness Scale ratings throughout the six continuous weeks of the study.

**Summary of Results:** At baseline, caregivers and dementia patients showed evidence of clinically significant sleep disturbance. For caregivers, total sleep time per night increased significantly, subjective sleep quality improved, and total time in bed per night increased during respite care. Comparing caregivers who shared a bedroom with the patient to those that did not, the former group showed less change in total sleep. For patients, respite was associated with increased sleep onset latency, reductions in total sleep time per night, and weakening of circadian activity rhythm compared to baseline. All outcomes were not sustained, shifting in the direction of baseline levels at follow up.

**Study Limitations (as cited by authors):** The authors note that the absence of serial measures of caregiver mood and the short (2 week) follow-up period in this study limit the inferences that can be drawn from the data. Further, they suggest that “while the present findings offer a valuable, pragmatic and adequately powered design, a randomized controlled trial could provide a more rigorous test of respite care effect.”

**Authors’ Discussion/Conclusions:** “As one of several services supporting caregivers and patients in the community, institutional respite offers the potential to improve quality of sleep and quality of life for dementia caregivers…. Future research could usefully focus on strategies that optimize the sleep quality of patients in respite care and broaden and maintain these demonstrated benefits in spousal and nonspousal caregivers. Such research should also recognize the multidimensional nature of caregiver burden and explore the relative contribution of sleep quality to the demands and satisfactions of providing care.”

**Study Aim/Purpose:** The aim of this study was to evaluate the impact of a multi-component support program for caregivers of adults with aging Veterans with disabilities, implemented through a Veterans Administration site in Tampa Florida. The program included 24-hr in-home respite care, caregiver group support, and education/skills training. Caregivers had the option to receive services for 14 consecutive days.

**Summary of Methods:** Researchers used a pre-/post design involving interviews with a sample of 42 veteran/caregiver dyads prior to the receipt of services and two weeks after program use. Data were collected on caregiver and veteran care recipients’ demographic and health characteristics, caregiver satisfaction with support services (using the Client Satisfaction Questionnaire), caregiver perceived physical and mental health status (using the SF-12 to measure physical and social functioning, role limitations, pain, vitality, distress and well being), positive aspects of caregiving (using the Positive Aspects of Caregiving Instrument), and caregiver burden (using the Zarit Caregiver Burden scale).

**Summary of Key Results:** Participants in the study used an average of 10 days of in-home respite services, with use ranging from 1-13 days. Caregivers reported high satisfaction with services and “the use of services over consecutive days was a consistent positive comment that caregivers made (open-ended responses) with regard to the helpfulness of the program.” Caregiver mental health improved significantly from pre to post-test. While mean caregiver burden did not show statistically significant improvement, bivariate analyses comparing “clinically meaningful improvement in burden (4 points on the Zarit scale) versus no clinically meaningful improvement showed that a statistically greater proportion of women experienced a clinically meaningful improvement in caregiver burden than women who did not.” Multivariate analyses found that worse physical health of the care recipient at program onset was significantly associated with the caregiver experiencing a clinically meaningful improvement in burden. There was also a trend toward a clinically meaningful improvement in burden for caregivers who had provided care for a long duration of time. Other measures did not differ significantly from pre to post-test.

**Study Limitations:** The authors cited the short follow-up period, small sample size, and lack of a control group as limitations of the study design.

**Authors’ Discussion/Conclusions:** The study findings “can be used to identify and target veteran/caregiver dyads within which a short-term, yet consecutive break with support services (including 24-hr respite) offered in the home would meaningfully improve caregiver burden. Additional research is needed to understand the long-term health status outcomes for caregivers who benefitted from a short-term break over consecutive days.” The authors suggest “a larger prospective randomized trial is needed to examine outcomes for caregivers and care recipients participating in this kind of program and to identify which components have the largest impact.”

**Study Aim/Purpose:** The study described and analyzed consistency between family caregivers’ desired and actual use of their time while their relatives were receiving adult day services. The study then sought to examine the relationship between this level of consistency (or inconsistency) and caregivers satisfaction with respite time-use, their feeling of burden, depression and satisfaction with caregiving.

**Summary of Methods:** The study collected information from 52 family caregivers age 50 and older using in-home interviews and respite activity logs filled out by the caregivers over a one-week period. The caregivers were recruited from three adult day centers in two moderately sized cities in the western United States. Each completed an initial interview that included demographic data and detailed information on their desired activities for the upcoming week during respite time. During the week they logged total respite time and actual use of respite time each day. After receiving respite services, they answered questions about their satisfaction with respite and provided information to measure the following outcomes: 1) caregiver burden (using the Multidimensional Caregiver Burden Inventory), 2) depression (using the Center for Epidemiological Studies Depression scale), and 3) satisfaction with caregiving (using the Caregiving Appraisal Instrument).

**Summary of Key Results:** The caregiver responses indicated that caregivers “pursue a wide range of activities during respite time” and there was a strong association with respite satisfaction and how consistent caregivers were in doing the types of activities they wanted to do during their respite time. Caregivers who were very satisfied with their respite time also had significantly lower depression scores than those who were not very satisfied. Likewise the high consistency group (i.e. highly consistent in actual vs. desired activities) had significantly lower depression scores compared to those who were not as consistent in their time-use during respite. Furthermore, depression scores were highest among the group of caregivers who had both low consistency in use of respite time (actual vs. desired) and low satisfaction with their respite time.

**Study Limitations (as cited by authors):** The authors cite the small and homogenous sample, the limited age of caregivers included, and the one-week data collection period as limitations of their ability to capture the dynamic aspects of caregiving circumstances and experiences. In addition, the study focused exclusively on those who used adult day services for respite. Other forms of formal and informal respite were not included. Lastly, how study participants differed from those who declined to participate was unknown.

**Authors’ Discussion/Conclusions:** The authors recommend that, based on their study findings, more attention should be paid to helping caregivers carry out satisfying activities during available respite time. They recommend that providers and researchers help respite users in the following ways: “(a) assessing their situations, resources, and needs; (b) determining what types and amount of respite activities might be most beneficial to them given their preferences and areas in which their lives are being most negatively affecting by caregiving; c) setting specific goals for how to use their upcoming respite time;
(d) developing a plan to make their goals achievable...; (e) evaluating the effectiveness of the outcomes of respite; and (f) making goal setting and evaluation ongoing activities...” In terms of future research, the authors suggest “that studies place an emphasis on theoretically based interventions and longitudinal designs that are tailored to the individual needs of each caregiver...Also needed are studies that assess diverse forms of formal and informal respite services and include more diverse populations and provide appropriate culturally sensitivity to the ethnic and racial differences among caregivers.”

**Study Aim/Purpose:** The authors state that the primary aim of the study was to investigate whether day care programs in Sweden positively impacted caregivers of relatives with dementia, with specific regard to feelings of worry, burden, overload and depression, physical difficulties, and psychological well being.

**Summary of Methods:** The study design was a pre/post analysis of change among caregivers. Fifty-one caregivers in 49 day care centers were recruited and met the inclusion criteria for the study (i.e. diagnosis by a physician as suffering from dementia or memory problems associated with dementia, ability to interview the caregiver no later than the client’s fifth visit to day care, and the relative was the dementia sufferer’s main caregiver though not necessarily co-residing). Data were collected at baseline and 4 months post through at-home interviews. Outcome measures were: 1) depression, somatic problems, and psychological well-being (measured by parts of the Center for Epidemiological studies Depression scale questionnaire; 2) self-perceptions of role captivity and worry (measured by level of agreement with items developed for the present study and a 1998 study in America); and 3) caregiver overload (including four items developed by Pearlin, et al (1990) and three developed for this and the 1998 American study mentioned above).

**Summary of Key Results:** Feelings of role captivity, worry and overload significantly decreased for all groups of caregivers after 4 months of day care. Within this group, “those who started with a high score for negative and difficulty feelings seemed to be helped less by day care than those who had lower scores from the start.” At the same time, continuation of day care had no significant association with changes in the depression scores for all caregivers; however, among the subgroup of caregivers who did not reside with their family member with dementia, depression levels were reduced among those who continued with day care compared to those who discontinued day care use during the study period. In a regression model, “no significant associations were found between any single feature of caregivers and care recipients and whether they continued day care.”

**Study Limitations (as cited by authors):** Authors cited the small sample size as a limitation in the ability to generalize the study findings.

**Authors’ Discussion/Conclusions:** The authors conclude from their findings that day care “seems most appropriate for those who reside with the care recipient” and “of greatest benefit to caregivers who experience less worry, overload and role captivity from the start.” With regard to practice and policy recommendations they state that: “The challenge is for the authorities to identify those caregivers (who benefit most from day care) while providing other caregivers with other forms of support, for example home help services or short-term residential respite care.”

**Study Aim/Purpose:** The aim of this study was to examine the impact of residential care on disruptive behavior displayed by older adults, particularly those with dementia.

**Summary of Methods:** The study used a quasi-experimental, longitudinal, single group design. Over a 12-month period, 100 older adults (mean age of 81.8 years), who were admitted to one of several residential aged care facilities in a provincial Australian city, and their caregivers were included in this study. Baseline data were obtained for each respite recipient when the respite session was booked at admission and the frequency of their disruptive behavior was rated on the Dementia Behavior Disturbance Scale (DBDS) by the home caregiver who had the most regular contact with the respite recipient and the primary nurse in the residential facility. Data for the DBDS were collected on three occasions, 1) fortnightly, prior to the subjects entering the residential facility; 2) one to four occasions weekly during the respite care, depending on the duration of respite care; and 3) and at one and two months post-respite.

**Summary of Key Results:** Time series regression analysis “confirmed significant differences in mean DBDS scores across time.” Specifically, residential respite care was associated with a lower DBDS score during the first week in residential respite care than compared to pre-respite. “In addition, the DBDS score for four weeks of residential respite care was significantly lower than for the two post-respite data collection points.” Thus, while respite had a short-term impact on the frequency of disruptive behavior in older people, “respite had no enduring impact on behavior.”

**Study Limitations (as cited by authors):** “There were different raters when the respite recipient was at home and in the residential aged care facilities... Although we had previously shown good inter-rater reliability between these groups of raters, it remains possible that the nurses had a higher threshold than the home caregivers for rating disruptive behavior.” The authors also pointed out that the study was not a randomized controlled trial, and the study sample was not ethnically diverse.

**Authors’ Discussion/Conclusions:** Despite the study limitations the authors note that this study used a strong longitudinal prospective repeated measures design and a reasonably large sample size. The authors state that their finding of the temporary reduction in the frequency of disruptive behavior while in respite care “should reassure both family carers considering placing a relative in residential respite care and health workers considering whether to recommend such a course of action.”

**Study Aim/Purpose:** This study explored family caregivers’ experience with a pilot weekend respite program in western Canada. The program provided respite care in a homelike environment for persons with Alzheimer’s Disease.

**Summary of Methods:** The authors conducted a qualitative assessment using multiple data collection methods. The data presented in this article were collected through telephone interviews with 19 caregivers. The interviews were conducted using a series of open-ended questions to learn about how caregivers used their time while their family member was attending the respite program and the caregivers’ views of the respite service and how it benefited their family member. The authors reviewed and coded the text in the interview transcripts to identify common themes.

**Summary of Results:** The authors point out three areas of common themes or findings. First, the caregivers frequently reported that respite provides time for them to maintain their own health, maintain family and social relationships, and catch up on sleep and rest. Second, a common theme was the relief from stress and worry that the program offered for the caregiver. Finally, caregiver relief was found to be largely tied to their perception that family members enjoyed the respite care experience and that they were safe and comfortable there. At the same time, caregivers noted the difficulty of transitioning their family member to the program, though they perceived the physical and emotional benefits to their family member as outweighing the costs to them of this short term stress.

**Study Limitations (as cited by authors):** The authors recognize that the small size and design of their study does not allow for generalizability of the findings.

**Authors’ Discussion/Conclusions:** The authors close the article by stating “that more traditional approaches to respite care could be replaced by models that focus on the experience of the caregiver.” They further recommend an “approach that reflects the findings regarding the caregivers’ needs for security and quality of care for their family member” which “could help maintain family identify and reduce the feeling of abandoning or ‘handing over’ a loved one.”

**Study Aim/Purpose:** The purpose of this study was to assess the association between participation in an adult day health center (ADHC) in the San Francisco Bay Area and quality of life for the participants who suffer from multiple chronic conditions and functional limitations.

**Summary of Methods:** The study used a prospective case/comparison group design collecting information from older adults within three weeks of enrollment in an ADHC and then 12 months later. The intervention group was 57 newly enrolled participants who attended ADHC two or more days and the comparison group was 67 community-dwelling older adults from the same geographic area who did not attend ADHS, but would have met eligibility criteria for attendance if referred. Interviews were conducted in the primary language of the participants (English, Cantonese, or Mandarin), allowing participants to respond either verbally or by pointing to a response choice on a card printed in a large font. Quality of life, the study’s primary outcome, was assessed using the Medical Outcomes Survey Form (SF 36). Participants’ ability to perform ADLs was assessed using the Physical Self-Maintenance Scale. Cognitive status was assessed using the Mini-Mental Status Examination. Depression was assessed using the self-reported Geriatric Depression Scale, and comorbidity was assessed using the Charlson Comorbidity Index.

**Summary of Results:** ADHC participation was associated with perceived reductions in the extent to which participants’ physical and emotional health problems affected their regular daily activities. Secondary analyses showed that changes in daily physical functioning, depressed affect, or cognitive functioning did not explain the improvements found in the two quality of life domains for the ADHC participants.

**Study Limitations (as cited by authors):** The authors note that although they measured and controlled for many factors likely to predict quality of life, it is possible that unmeasured differences, such as aspects of the individual’s living situation or receipt of services other than home care, could have over- or under-estimated the increases in quality of life attributable to ADHC participation. They also note that a definitive evaluation of ADHC would require a randomized controlled trial, but note that in most extant RCTs of ADHC the participants received only small dosages of ADHC and the studies thus have had mixed outcomes.

**Authors’ Discussion/Conclusions:** A possible explanation of the study results presented by the authors is that “the multilevel ADHC approach provides a social and physical environment tailored to participants’ functional level in which participants are able to comfortably meet the demands of the environment. In contrast, individuals with functional limitations who do not attend ADHC may experience more problems in everyday functioning because they are predominantly in an environment with demands that exceed their competence level.” In terms of future evaluation research on ADHCs, the authors recommend more research “to better understand the dose-outcomes relationship of ADHC attendance on participants.”

**Study Aim/Purpose:** The study sought to investigate caregiver and patient satisfaction with respite provided by adult daycare centers in the Netherlands, and patient and caregiver factors related to caregiver well-being.

**Summary of Methods:** This cross-sectional study conducted a one-time survey with a sample of 108 caregiver and patient dyads who had been enrolled in a daycare activity center for a mean of 4.8 years. The sample consisted primarily (70%) of stroke patients. Key outcomes measured were: satisfaction with the daycare activity center (using measures developed by the authors), life satisfaction (measured by the Life Satisfaction Questionnaire), emotional functioning of the caregivers and patients (measured by the Dutch Hospital Anxiety and Depression Scale), and caregiver self-report of burden (measured by the Caregiver Strain Index). In addition to demographic characteristics, characteristics of the day care center and of the patient’s ABI, they also measured the extent of caregiver and patient passive coping mechanisms --which the authors state are indicative of not taking any action when problems occur-- (measured by the Utrecht Coping List Passive reactions scale), and caregivers’ and patients’ sense of mastery over their own life (measured with the Mastery Scale).

**Summary of Results:** Satisfaction with the day-care activity center care was high for caregivers and patients. Caregiver satisfaction with care was found to be unrelated to the measures of life satisfaction or emotional functioning for either caregivers or patients: 61% of caregivers reporting low life satisfaction and high subjective burden, 40% of caregivers experiencing anxiety symptoms, and 33% of caregivers and 42% of patients reporting depressive symptoms. Caregiver well-being was positively associated with a high sense of mastery over one’s life among caregivers and patients and low measures of passive coping among the patients, but not with the patient’s ABI or the day-care activity center characteristics. When examining associations between ABI characteristics and outcomes, only level of caregiver burden was predicted by the severity of physical disabilities of the patient.

**Study Limitations (as cited by authors):** The authors note study limitations that should be considered when generalizing results to broader groups of patients with ABI, including: the cross-sectional study design, the lack of information on patient or caregiver use of other services, and the purposive exclusion of aphasia patients from the study sample. In addition, they note that the caregiver and patient received the questionnaires in the same envelope which may have influenced their responses.

**Authors’ Discussion/Conclusions:** The authors conclude that “the results of this study suggest that for better caregiver functioning, interventions should target mastery and coping skills of both caregivers and patients.” “In the current study, patients were already in the chronic phase of their injury, and a more constructive approach in this group should stress self-management of the consequences of brain injury and continuous support for both caregivers and patients” with ABI after the acute phase and discharge from the hospital or rehabilitation center. With regard to future research, the authors
recommend research to “provide knowledge about the contribution of each component and type of (respite) care to the well-being of caregivers and patients.”

**Study Aim/Purpose:** The purpose of this study was to examine whether and how receipt of a psychoeducational training program called the Savvy Caregiver Program (SCP), receipt of a respite voucher-type grant, and receipt of a combination of both services impacted caregivers and their use of other support services beyond the intervention. Both types of interventions were conducted by the Alzheimer’s Association Colorado Chapter.

**Summary of Methods:** This pre/post multi-group study was conducted with a total of 367 caregivers of persons with Alzheimer’s or other dementias in three treatment groups: 127 in SCP, 197 receiving respite grant, and 43 participating in both, with 184 participants completing the initial and follow-up surveys. The initial information was collected as part of the routine client intake questionnaires and follow-up was conducted both immediately after the SCP training in the form of a questionnaire and telephone interviews were conducted at 6-months follow-up.

**Summary of Results:** With regard to caregiver outcomes, average depression scores decreased significantly from baseline to the 6-month follow-up interview, regardless of treatment group. Overall health was found to significantly improve as well with significant correlations found between overall health and average depression scores. The authors also found increased support service use and support group usage among participants in the respite grant group and the group that participated in both SCP and the respite grant program. Participants in the combined treatment group showed positive findings for the three outcomes with no significant advantage over the SCP or respite grant group regarding depression scores or support group usage. Additionally, no significant associations were found between varying caregiver characteristics and the outcomes studied, with the exception of the finding that those living in urban areas had greater increases in support service usage than those living in rural areas.

**Study Limitations (as cited by authors):** Limitations of this study cited include absence of random assignment to the treatment groups, absence of a control group, lack of ethnic diversity in the sample, and constraints in the format of the questions used at intake because they were questions required by the federal grant program funding these interventions.

**Authors’ Discussion/Conclusions:** The authors highlight that participants in all treatment groups showed improved depression scores and increase in usage of support types of services. They state that the latter finding “is particularly noteworthy for the SCP group” and suggest that “contact with the Alzheimer’s Association and other caregivers in a similar situation was enough to bring about increased usage of support services.”

**Study Aim/Purpose:** The primary objective of this study was to describe and compare how employed and nonemployed caregivers of older adults spend their time and are satisfied with their use of time while their family members are in adult day respite center care. The benefits caregivers received from their respite time-use as well as how they thought they might be able to use this time more effectively were also examined.

**Summary of Methods:** The study used interviewed 48 caregivers using adult day respite in the western United States, of which 26 had paid employment and 22 were not employed. The data were collected through interviews that involved “three fixed-choice questions,” open-ended questions and a 4-day activity log, in which caregivers logged the amount of time they spent on a list of 19 different activities and how much time they would have liked to spend on each activity during their respite time (actual vs. desired time-use).

**Summary of Results:** Employed caregivers were generally more satisfied with respite time-use than nonemployed respite users and employed caregivers were also more likely to do activities that they desired to do. On the other hand, 40% of the nonemployed group felt they could have used their respite time more effectively. “Almost all of the employed caregivers mentioned “employment” or “work” as the number one most helpful or anticipated way to spend respite time,” yet most also said that lack of free time outside of work and caregiving were stressful and they desired more respite time. Nonemployed caregivers wanted to use their respite time better to reduce feelings of “wasted time and opportunity.” Employed and nonemployed caregivers reported similar levels of caregiver burden. As a result, caregiver burden did not confound the relationship between employment status and time-use patterns during respite.

**Study Limitations (as cited by authors):** The authors note the small sample size of their study and its lack of generalizability, while stressing the strength of its qualitative and exploratory nature including personalized accounts of caregivers’ time-use patterns and perceptions of the benefits of respite time.

**Authors’ Discussion/Conclusions:** The authors recommend that “future studies using a larger sample should explicate the relationship between time-use consistency (actual vs. desired) and mental health, while controlling for the factors that may select caregivers either into employed or nonemployed roles.” The authors recommend that practice and policies focus on enhancing caregivers use of respite time, including increasing respite time and providing assistance to caregivers to help them set goals and plan in advance how to best use their respite time which in turn “may allow caregivers to be more effective and fulfilled in their caregiving role...”

**Study Aim/Purpose:** This study, part of a broader evaluation of 14 adult day programs in Alberta, Canada, sought to measure the impact of the programs on the caregivers of elderly relatives and the degree of caregiver satisfaction with the program.

**Summary of Methods:** A time series research design was used with caregivers of adult day program participants interviewed in their own homes at four time points: just prior to client admission, 2 weeks, 2 months, and 6 months after admission. The following outcomes were assessed through a primarily quantitative survey instrument: 1) caregiving burden (measured by the Caregiver Burden Inventory), 2) quality of life (measured by the Self-Anchoraging Striving Scale), 3) perceived health (measured by asking for a subjective report of current health on a continuum from 1 (excellent) to 6 (poor), and 4) opinion on institutionalization (measured using a single question with Likert scale response options). Their satisfaction with the day program was measured at the 3 time points after client admission (measured using the Day Program Satisfaction Scale, developed by the researchers). A total of 61 caregivers completed the first measurement, 110 completed the second, 91 completed the third and 80 completed the final measurement.

**Summary of Results:** “Caregiver status on burden, quality of life, and perceived health status remained stable over time. In addition, caregivers’ opinions on institutionalization remained negative and satisfaction with the programs high. Caregivers reported that client socializing and improved health were what they liked best about the program, followed by respite for themselves. Time conflicts/limits and transportation were identified as problems.”

**Study Limitations (as cited by authors):** The authors note the lack of a control group in the study as limiting its generalizability, though they suggest that the baseline measure taken before admission serves as a form of control. They also suggest that “it is possible that some of the tools used to measure family caregiver outcomes were not sensitive enough to detect improvements over time.” They also note that the low moderate burden scores, moderate quality of life scores and good health scores of caregivers at baseline may not have allowed for room for improvements sufficient to detect significantly.

**Authors’ Discussion/Conclusions:** With regard to future research, the authors suggest studies of the impact of adult day programs on client-caregiver relationships, opportunities to interact with other caregivers, and relationships with health professionals.

**Study Aim/Purpose:** The purpose of this study was to compare the in-home respite experiences of caregivers using the direct pay mode of California’s Caregiver Resource Centers (CRCs) respite program (which is consumer-directed and gives caregivers vouchers to hire and manage their own respite workers) to pay family or friends to provide respite with caregivers who hired respite aides from a homecare or other agency.

**Summary of Methods:** Questionnaires were mailed to eligible family caregivers who were responsible for the day-to-day care of a cognitively impaired adult living in the community and receiving in-home respite from a CRC at the time of the study. Completed data were received from 168 respondents, 39 of whom hired family or friends as their respite provider and 77 of whom hired respite aides from a homecare or other agency. Questionnaires collected information on the characteristics of the respite users and care receivers, respite preferences, level of caregiver involvement in supervising his or her aide, satisfaction with respite care, and level of caregiver distress and depression (the latter measured by the Center for Epidemiological Studies Depression Scale). Caregiver respite use and cost data were obtained from the CRC automated data system used to track service usage and expenditures.

**Summary of Results:** Caregivers who hired family and friends as respite aides were found to be very similar in their demographic characteristics and levels of mental health and distress to caregivers who hired respite aides from agencies, with a few exceptions: caregivers who hired family and friends were slightly more likely to report worse current health than five years previously, to report “health problems getting in the way of doing things,” to have slightly higher levels of satisfaction with the respite assistance they received, and to have exercised more control and choice in the day-to-day management of their in-home respite aides. The study findings also indicate that hiring family and friends was less costly per hour of service than hiring service providers ($8.48 per hour versus $12.67 per hour) and that these caregivers received more hours of respite assistance per week (9.1 hours versus 7.7 hours per week).

**Study Limitations (as cited by authors):** None cited.

**Authors’ Discussion/Conclusions:** The authors conclude by saying, “To meet the changing needs of family caregivers, practitioners must offer families access to a range of service delivery options, assess for the caregivers’ preferences and abilities to direct the day-to-day management of in-home respite care, and give the caregivers the choice to hire family and/or friends as respite aides.”

**Study Aim/Purpose:** The objective of this study was to examine the effects of adult day service (ADS) programming in New Jersey on exposure to and emotional response to stressors for family caregivers of individuals with dementia.

**Summary of Methods:** This study used a “within-person withdrawal design” using 24-hour daily diaries (using the Daily Record of Behavior, an expanded version of the widely used Revised Memory and Behavior Problems Checklist) completed by 121 caregivers (primarily spouses and adult daughters). Two days of consecutive diaries were used to measure care related stressors at baseline (for two days prior to ADS use) and for two ADS-use and two non-ADS use days, each at one month and two months after beginning the program. In-home interviews were also conducted to assess caregiver and patient characteristics, measure severity of dementia and the patient’s functioning on ADLs and IADLs, and to collect information on frequency of behavioral, memory, and mood problems that occurred in the past week.

**Summary of Results:** Analysis found that after one and two months of ADS use, the mean total exposure of caregivers to stressors stayed approximately the same on non-ADS days, while exposure on ADS days went down from just over 2 hours each day to 75 minutes at one month and to 52 minutes at two months. Most of the difference was accounted for by the time the person with dementia was away from the caregiver, but there were also significant reductions in behavior problems for the person with dementia during the evening and improved sleep immediately following ADS use. Additionally, the average reported length of caregiver upset per behavior problem decreased significantly across all days over the two-month period.

**Study Limitations (as cited by authors):** Although the authors suggest their “within-person withdrawal design” is a strong study design for examining the effects of an intermittent intervention such as respite, they also point out several limitations to their study including: the small sample size, sample having higher levels of education and income than the population of the state as a whole, daily assessments not including measures of caregivers’ own emotional distress or health symptoms, and the fact that the authors were not able to test the effects of order of ADS and non-ADS days or lagged or cumulative effects of ADS use.

**Authors’ Discussion/Conclusions:** The authors suggest the following implications of their study findings for respite programming: “By reducing behavioral problems and improving sleep in people with dementia, even in small amounts, ADS and other activity-based programs may be of considerable value to caregivers and may help keep their relative at home for a longer period of time.”

**Study Aim/Purpose:** The objective of this study was to examine the effects of adult day service (ADS) programming on reported daily stressor exposure, affect, and health symptoms of caregivers of individuals with dementia (IWD).

**Summary of Methods:** This study used a “within-person withdrawal design” with a sample of 173 relative caregivers of IWD in New Jersey, the Philadelphia and Pittsburgh metropolitan areas, northern Virginia, and Denver, Colorado. Data on caregivers’ daily experience of care-related stressors, non-care stressors, positive events, anxiety symptoms, anger, depressive symptoms, positive effect, and health symptoms were collected during evening telephone interviews for 8 consecutive days.

**Summary of Results:** Multilevel models indicated that caregivers reported significantly lower care-related stressors on ADS days compared with non-ADS days. Caregivers’ experiences of non-care stressors were significantly higher on ADS days as were their experiences of positive events on ADS days. Examining the association of stressors with caregiver affect and health symptoms, researchers found both types of stressors were associated with more depressive symptoms, anger, anxiety symptoms, and health symptoms, whereas positive events were associated with fewer of these daily affects and health symptoms. Additional analysis of the interaction between total number of ADS days used and daily affect found that among caregivers who reported higher care-related stressors, ADS use had a buffering effect on depressive symptoms.

**Study Limitations** (as cited by authors): Although the authors suggest their “within-person withdrawal design” and measures of daily ADS use and daily stress, affect and health are components of a strong study design for examining the effects of an intermittent intervention such as respite, they do suggest that there could be potential selection bias in a study sample that includes only volunteers who already used ADS.

**Authors’ Discussion/Conclusions:** The authors suggest both the importance of understanding the daily effects of ADS use and the need to build upon these findings in future research. They highlight the importance of research to measure the long-term impacts of respite programs, including differences in response to ADS dosage and the cumulative effects of ADS use.

**Study Aim/Purpose:** This study examined the effects of adult day service (ADS) use on caregiver relatives living with individuals with dementia (IWD) on the caregivers’ level of a salivary biomarker of stress reactivity as well as the association of the biomarker levels with variability in reported symptoms of positive mood and depression.

**Summary of Methods:** This study used a “within-person withdrawal design” with a sample of 151 caregivers of IWD using ADS in 57 sites in northern and central New Jersey, the Philadelphia and Pittsburgh metropolitan areas, northern Virginia, and Denver, Colorado. For eight consecutive days—including days of ADS use and days of non-ADS use—researchers collected the following kinds of data: 1) saliva samples (5 per day) to determine daily levels of dehydroepiandrosterone-sulfate (DHEA-S); 2) self-reported levels of care-related and non-care related stressors and positive events; and 3) depressive symptoms and positive moods. The latter two were assessed during daily telephone interviews. Factors including age and gender of the caregiver, medications the caregiver was taking, duration of caregiving, the IWD’s ability to perform activities of daily living, and total days of ADS use over the study period were also included as between-person covariates in the statistical analysis.

**Summary of Key Results:** Analysis found care-related stressors were lower on days the IWD attended ADS and that ADS use was associated with increased DHEA-S levels on days after ADS use (whether or not the person used ADS or not on those “days after ADS use”). The effect size was small but significant. They also found that days with positive moods were associated with the higher daily DHEA-S, though daily ADS use was not associated with reported positive moods. At the same time, total ADS days used was significantly related to higher mean positive moods. Daily depressive symptoms were not associated with daily DHEA-S.

**Study Limitations** (as cited by authors): Although the authors suggest their “within-person withdrawal design” is a strong study design for examining the effects of an intermittent intervention such as respite, they also point out several limitations to their study including: 1) the fact that the sample were volunteers who were already using ADS may have selectively included those who experience a positive response to ADS; 2) the lack of measurement of duration of caregiver exposure to stressors; 3) the short study period; and 4) the predominance of women in the sample as the effects of DHEA-S levels differ by gender.

**Authors’ Discussion/Conclusions:** The authors note that this is “one of the few studies demonstrating an effect of a caregiving intervention on physiologic indicators of stress.” While recognizing that effect size was small in this study, the authors suggest broadening the focus of evaluations of caregiver interventions “to include their impact on relevant biologic risk factors associated with chronic stress and disease.”
III. Studies of the outcomes of respite targeted to adults with developmental disabilities


Study Aim/Purpose: The study had two main objectives. First, it sought to explore associations between the amount of family control in the management of paid respite/personal assistance services for families of individuals with developmental disabilities (DD) and five outcomes: caregiving burden, caregiving satisfaction, caregiving self-efficacy, satisfaction with the service, hours of weekly employment of the mother, and community involvement of the individual with DD. Second, the study sought to compare outcomes for families who hired relatives to provide respite/personal assistance to those who hired non-relatives.

Summary of Methods: This study used a cross-sectional design with data collected through a survey completed by 97 families receiving paid respite or personal assistance from the Illinois Home Based Support Services Program. The researchers defined level of family control in the management of respite/personal assistance services by rating caregiver responses to survey questions in six areas: recruitment of individuals providing the service; hiring and firing of individuals; training of individuals; deciding what activities are performed; deciding the days/time services are provided; and determining the wages of individuals providing services.

Summary of Key Results: Statistical associations were found between more control by families in the management of their respite/personal assistance services and 1) increased service satisfaction; 2) increased community involvement of individuals with DD; and 3) increased employment of mothers. The majority of families in the study hired other relatives to provide services and there was a significant positive association between hiring relatives and increased community involvement of individuals with DD.

Study Limitations (as cited by the authors): The authors suggest that some of the measures they used may have been weak and specifically note the low reliability of their measures of caregiving self-efficacy and community involvement.

Authors’ Discussion/Conclusions: “While there are individual considerations in the amount of control desired by people with disabilities and families, the present study suggests that policies should allow flexibility and consumer direction when desired.” The authors make recommendations for future research including studies to better explore the preferences and outcomes surrounding community inclusion of persons with DD, health outcomes of respite, and outcomes associated with hiring other family members to provide services. They also recommend that future research include the perspectives of persons with DD and explore how much control these individuals have in hiring and directing staff and how they feel about hiring other relatives.

**Study Aim/Purpose:** The study aims to describe the use of publicly funded respite care in Taiwan and caregivers’ satisfaction with those services. The study’s purpose was also to measure the effects of respite use on caregivers’ burden and factors that may contribute to positive effects of respite.

**Summary of Methods:** 116 primary family caregivers who lived with an adult (age 15 +) with an intellectual disability (ID) and recently used the Taiwan respite care program completed interviews in their home. The interviews collected household demographics and information on why and how families used respite care, their access to information and resources, and information on caregivers’ level of burden prior to and after respite use.

**Summary of Key Results:** Prior to using respite care, the majority of caregivers reported one or more of the following difficulties: having no one to help with caregiving, not having an opportunity for a break, sleeplessness, constant care-giving, inability to go out, having no time of one’s own, feeling depressed, feeling anxiety, neglecting the care of other family members, and pressure on family relationships. “Furthermore, 77.6% of caregivers reported that they were not satisfied with their life.” After using respite care, “a clear majority of the participants responded that their life was ‘somewhat better’ or ‘very much better’ within each of the seven domains”—with the most common improvements in the areas of social support, psychological stress, life satisfaction, and overall burden. Using regression analysis, the authors report that satisfaction with care and the co-payment arrangements were statistically associated with improvements in caregiver social functioning. Further, respite users who reported having a religious belief and lived in a metropolitan city were more likely to have their overall burden of care relieved by respite, improved family interaction, and better access to information and resources than users who had no religious belief and lived in non-metropolitan areas.

**Study Limitations:** One key study design limitation noted by the authors was that caregivers were interviewed only once to collect the pre and post respite information, with the reported level of burden prior to respite use based on their ability to recall that information.

**Authors’ Discussion/Conclusions:** “It is perhaps surprising that religion emerged as a significant factor associated with effectiveness of respite use. Whether the non-religious caregivers were also more likely to be isolated from social networks, and more disadvantaged with respect to family interaction and assistance with the burden of care, needs to be clarified by future studies.” They authors suggest that their study be viewed as preliminary results and hope that it “serves as a stepping stone for further research on a much-needed service.”
IV. Literature Reviews/Meta-analyses of Respite Care Studies


**Study Aim/Purpose:** The purpose of this paper was to consider the definitions and assumptions that underpin the term respite and its impact on the physical, psychological and social outcomes of carers in palliative care contexts.

**Summary of Methods:** The literature review, which involved searching five electronic databases (Web of Science, Medline, CINHAHAL, Cochrane Database System Review and Social Sciences Citation Index), identified a total of 260 peer-reviewed journal articles in English focused on adult respite services, of which 28 related directly to adult respite care in palliative care contexts. The search strategies used the following key words: ‘palliative care’ or ‘terminal care’, or ‘end-of-life care” or “hospice”or “palliative day care”, or “palliative home care” and “respite care”, and “informal carers” and “family carers.”

**Summary of Key Results (related to studies of effectiveness):** The authors found “no empirical studies assessing the effects of specialist palliative respite care intervention on carer wellbeing.” They state that “what research evidence there is about carers is largely derived from those caring for older people with long term, but not immediately terminal illnesses.”

**Limitations of Studies Reviewed** (as cited by the authors): The authors raise several conceptual and methodological problems with studies on the effects of palliative respite care on carer well-being. For example, they state that applying outcome indicators to evaluate the effectiveness of respite in palliative care necessitates clear definitions of the content and model of services, yet there is little known about these features beyond that respite is delivered in a wide range of settings and there are wide variations in the pattern of specialist and non-specialist and voluntary and statutory services. Also, they note that research in the family caregiving literature has focused on the negative or pathological aspects of care to the relative while disregarding sources of satisfaction and reward. They suggest a more balanced approach “which recognizes both challenging and positive perceptions of family care giving and satisfaction with roles.”

**Authors’ Discussion/Conclusions:** The authors state that “there is insufficient evidence to draw conclusions about the efficacy of offering respite care to support carers of patients with advanced disease.” They also point out that their review “indicates that little attention has been devoted to examining the impact of interventions such as respite on the carer rather than the patient. The views of carers have been frequently elicited in palliative care research, but generally as proxies for patients rather than in their own right.”

**Study Aim/Purpose:** To review research literature on respite for people affected by severe mental illness and identify implications for nursing practice.

**Summary of Methods:** An initial literature search was undertaken using the key words ‘respite’, ‘short-term care’, ‘shared care’ and ‘day care’ for literature published in English between 1967-2002 in PsycINFO, CINAHL, Sociological Abstracts, APAIS (Australian Public Affairs Information Service) Health, Pre-MEDLINE, MEDLINE, EMBASE and EBM Reviews. The authors conducted a closer examination for the literature from 1993-2002 on respite care for people affected by severe mental illness.

**Summary of Results:** Based on the broader literature search the authors conclude that, “There is a significant lack of controlled empirical studies examining the effectiveness of respite care services. In particular, no evaluative literature on respite care for people with SMI and their families was found.” They did find several studies documenting the need for respite care among caregivers of people with severe mental illness. Because of the absence of evaluative studies on respite for persons with severe mental illness, the authors summarize some key findings from the literature on respite in the elderly population, which primarily focused on respite for caregivers of persons with dementia and Alzheimer’s disease. They conclude that “provision of respite services is found to increase caregivers’ satisfaction with respite programs and there is an increasing demand for them.” They summarize that studies on the impact of respite care focus on three outcomes: impact on informal family caregivers, impact on recipients of care, and impact on long-term institutionalization of care recipients. However, the authors’ review of these studies finds that “evidence on their effectiveness is inconclusive.” The authors also summarized selected studies that focused on the role of nurses in the provision of respite care. They cite some studies that found little involvement of nursing staff in working with family caregivers than other health professionals and one study which found that “the way nurses interacted with caregivers influenced the quality of caregivers’ experiences with respite care services, and hence benefits.” Other studies cited explored the nurse family relationship and nursing roles in both the assessment of families respite needs and how caregivers were involved in receiving respite care.

**Limitations of Studies Reviewed** (as cited by the authors): They state that despite the large number of studies on respite for caregivers of persons with dementia and Alzheimer’s disease, “Studies examining outcomes and effectiveness of respite series are either scarce or lack rigor.” The authors stress that the differences in respite care needs between carers of people with SMI and those with dementia have not been adequately addressed in respite care research to date.

**Authors’ Discussion/Conclusions:** The authors discuss several key implications of their literature review for nursing practice. They emphasize that “health care workers, and especially nurses, can help caregivers overcome some of the barriers and problems associated with the provision, access to and use of respite services” for persons with severe mental illness. They include specific recommendations for nursing practice to address these issues.

**Study Aim/Purpose:** The authors’ aim was to conduct a systematic review of the literature on the effectiveness and cost-effectiveness of community-based respite for caregivers of frail older people.

**Summary of Methods:** Authors searched 37 databases for studies from 1980 through March 2005, including databases of systematic reviews, old age and aging, health and social care, economics, conference proceedings, ongoing research, dissertations, and other gray literature. The searches were not limited by study design, outcome measure, disease area, or language. For the effectiveness and economic studies, data were extracted and study quality assessed by one reviewer and checked by another. For uncontrolled studies, one reviewer assessed quality and a second checked it using a quality appraisal checklist. The authors used meta-analysis to synthesize or pool the findings on similar measures from the controlled studies. Effect sizes of the pooled findings were estimated using standardized mean differences for studies assessing the same outcome but using different scales.

**Summary of Key Results:** The authors found 22 effectiveness and 5 cost studies that met inclusion criteria. Of the former group, ten used randomized controlled study designs, seven were quasi-experimental studies, and 5 were uncontrolled studies, included because no controlled study was identified for the type of respite or patient group studied. Of the cost studies, 2 conducted cost-effectiveness analysis and 3 analyzed costs or cost differences of respite vs. different or no care. Summarizing their results, the authors said: “Of the 17 randomized control and quasi-experimental studies, all but one compared the effect of a respite intervention with usual care. These studies provided usable data for only two caregiver outcomes—burden and depression.” They report that for all types of respite, the effects upon caregiver burden and caregiver mental and physical health were generally small, with better controlled studies finding modest benefits only for certain subgroups and “no reliable evidence that respite care delays entry to residential care or adversely affects frail older people.” At the same time, the authors found many studies that reported high levels of caregiver satisfaction with the respite they received. “The economic evaluations all assessed adult day services and found them to be associated with similar or higher costs than usual care.”

**Authors’ Discussion/Conclusions:** The authors conclude that “the existing evidence base does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn” for two principal reasons. First, there are serious problems with the methodological quality of many studies underpinning the evidence base…. Second, where better-quality evidence exists, the implications for other populations are unclear.” Furthermore, they note that the relative effects found in these studies are highly dependent on how the intervention and comparator (non-intervention) services were configured, resourced, delivered, and accessed.”

As to future research, the authors recommend pilot studies be conducted to inform full-scale controlled trials and that these studies “identify one or more target groups (i.e. caregiver and care receiver dyads), establish clear definitions of the services to be compared, and determine the main
outcomes to be measured, such as caregiver quality of life or institutionalization rate.” The authors suggest that future research should combine qualitative and quantitative methods.

**Study Aim/Purpose:** This meta-analysis sought to improve upon findings from extant evaluations of various interventions serving dementia caregivers by pooling the samples and analyses of intervention effects from studies that generally use small sample sizes and measuring more reliable mean effects.

**Summary of Methods:** Using a keyword search of electronic databases (Psycinfo, Medline, Ageline, and Psynex) and strict inclusion criteria, 127 articles were identified on interventions helping caregivers of persons with dementia. The inclusion criteria were as follows: 1) the care receiver being studied had dementia; 2) the intervention was compared to a control condition that did not receive the intervention; 3) one of the following outcome domains were reported: caregiver burden, depressive symptoms, indicators of positive subjective well being (e.g. life-satisfaction, happiness), knowledge and/or coping abilities of the caregiver, symptoms or outcomes of the care receiver, and/or institutionalization; 4) statistics could be converted into effect sizes; and 5) the study was written in English or German (or in two cases another language for which the authors could get translation).

The authors compared interventions that had been evaluated in five or more controlled studies and categorized according to the dominant component. If no dominant component was identified, the category for these interventions was labeled “multicomponent.” The dominant components identified were psychoeducational interventions, cognitive-behavioral therapy (CBT), respite, counseling/case management, general support, and training of the care receiver.

The authors reviewed 127 studies conducting statistical integration of the studies’ findings using random-effects models to compute average effects for most of the outcomes and a log odds ratio was used to compute the relative odds of the care receiver being institutionalized after exposure to the intervention. These analyses were conducted for each outcome across the types of interventions studied and for each type of intervention with a separate analysis for multi-component interventions. Analyses were also conducted of the studies’ characteristics to see how that may have affected findings.

**Summary of Key Results:** The authors’ outcome specific analysis across all interventions found that the interventions had statistically significant, but small immediate effects on caregiver burden, depressive symptoms, subjective well being, abilities/knowledge of the caregiver, and symptoms of the care receiver. Studies with follow-ups with an average time lapse of 11 months showed significant positive effect on caregiver burden, depressive symptoms and ability/knowledge. On the other hand, no significant effect of intervention was found on the risk of institutionalization. When the effect sizes were analyzed for specific kinds of interventions, the analysis showed that psychoeducational intervention had significant effects on all outcomes except institutionalization, with those requiring active participation of the caregivers (e.g. to practice or role-play what they learned) having the broadest effects. Cognitive behavioral therapy (CBT) had a small to moderate positive impact on caregiver burden and a large positive effect on caregiver depression, though the authors note that only one CBT study was available on the impact of CBT on caregiver depression. Counseling showed significant and moderately sized effects on burden, while supportive interventions (e.g. with group support groups)
improved subjective well-being. Training (e.g., on improving memory) of the care receiver had small significant effects on the symptoms of the care receiver. Studies on respite interventions also had small significant effects, specifically on caregiver burden, depression and subjective well-being. “Structured” multi-component interventions did not show significant effects on most of the outcomes, but were significantly related to delayed institutionalization for the care receiver. The authors also found that longer interventions were more likely to improve depression and to decrease the risk of institutionalization.

Comparing effect sizes by study characteristics, the authors found that studies with a higher percentage of caregiver women in the sample demonstrated greater improvements in knowledge/abilities, depression, and a greater delay of institutionalization, but less improvement in subjective well-being.

**Limitations of Studies Reviewed:** The authors note that there is insufficient research on sustained or long-term consequences of caregiver interventions. Additionally, they note that few studies focus on the positive aspects of caregiving, such as caregiver well-being or finding benefits in the caregiving role. They also note the lack of studies on mediators that may be causing the observed effects of the interventions, such as caregivers’ beliefs, coping strategies, or a reduction in the amount of care they need to provide.

**Authors Discussion/Conclusions:** Overall, the authors conclude that given their findings of small but meaningful effects of caregiver interventions, “there is a continued need for improvement in the quality of the interventions.” They recommend future long-term impact research as well as studies addressing the methodological limitations of the studies reviewed. The authors also stress the need for future research on individual differences in caregivers’ response to particular interventions. Finally, they suggest that more research is needed in multi-component interventions. Specifically, they recommend research to test whether a combination of individual interventions that their meta-analysis found effective, such as education or CBT with respite, would produce stronger positive effects on caregiver and care receiver outcomes or whether interventions with fewer components are better received by caregivers and therefore more effective.

**Study Aim/Purpose:** This international literature review aims to assess the existing research evidence concerning the impacts of short breaks on families with disabled children.

**Summary of Methods:** The authors conducted electronic literature searches using ASSIA, PsycInfo, CINAHL, and Web of Science, and also sent requests for information to selected email lists.

**Summary of Key Results:** Sixty articles and reports were identified for inclusion in the review. The majority of these studies were cross-sectional studies, with only 8 studies using quasi-experimental pre/post or longitudinal designs. Specific outcomes reported in the literature included the impacts of respite on carer well-being; impacts on child with disability receiving respite; impacts on siblings; and impacts on family functioning and on seeking permanent out-of-home placement. Despite finding methodological limitations of the research reviewed, the authors find that the “research consistently reports positive impacts of short breaks on the well-being of most (but not all) disabled children and their families.”

**Limitations of Studies** (as cited by authors): For studies reviewed, some of the methodological problems cited were: 1) limited use of quantitative outcome measures; 2) confounding factors in the comparison of short break users and non-users; 2) lack of a control group who did not use short breaks; 3) small sample sizes; and 4) the provision of short breaks in conjunction with other interventions.

**Authors’ Discussion/Conclusions:** The authors identify the need for additional research with the following goals: 1) evaluation of the impact of short breaks on fathers; 2) evaluation of the impacts of short breaks on the siblings of disabled children; 3) consideration of how short breaks can be combined with other interventions to maximize their impact; 4) assessment of the longer term impacts of short breaks for disabled children and their families; and 5) provision of evidence regarding the type of short breaks that are most effective for children and families with particular characteristics and for children at different ages or levels of maturation toward adulthood.

**Study Aim/Purpose:** This article provides a systematic review of published studies up through 2008. The review includes quantitative studies on the effectiveness and cost-effectiveness of respite on the well-being of informal caregivers of frail and disabled adults aged 65 years and older who live in the community. The review also summarizes findings of qualitative studies on these caregivers’ needs and views related to respite services and perceived barriers to utilizing respite.

**Summary of Methods:** Authors searched the electronic databases MEDLINE, EMBASE, PsychInfo, AMED, ASSIA, IBSS, CINAHL, Econlit, Social Care Online, Sociological Abstracts, Web of Science, Cochrane databases of reviews and trials, PubMed Cancer Citations, Scopus, and databases of ongoing research. Quantitative studies were included in the review if they: 1) assessed an intervention to provide the caregiver with a break from caring and assessed caregiver outcomes; 2) the care recipient population was aged 65 years or older or included subsample analysis of participants over age 65; and 3) the respite intervention was compared with no exposure to respite or with exposure to another intervention. The search resulted in finding 104 quantitative studies and the synthesis was carried out separately for each type of caregiver outcome reported. The review of qualitative studies used thematic analysis exploring similarities and differences in the findings of a total of 70 papers that were identified for inclusion, focusing on findings related to caregivers’ needs and factors influencing their use of respite care.

**Summary of Key Results:** The authors state that though the meta-analysis found “some evidence to support respite having a positive impact on caregivers”, “the evidence was limited and weak.” The following were key findings of impact on caregivers:

- Caregiver burden was reduced at 2-6 months’ follow-up in studies with single samples, but not in randomized control studies (RCT) or quasi-experimental studies.
- Caregiver depression was reduced in the short term in RCTs but only for respite home care, not respite provided in out-of-home day care.
- No effect was found on caregiver anxiety. However, respite did have positive effects on morale, anger and hostility. Single-group studies suggested that perceived quality of life may have been worse after respite use.

The separate analysis of qualitative studies found that uptake of respite care was influenced by a variety of factors including: caregiver attitudes toward caring and respite provision; the caregiving relationship; the acceptability to, and impact of respite care on care recipients; hassles resulting from the use of respite care; quality of respite care, and the appropriateness and flexibility of the respite provided. Most common needs reported by caregivers in the qualitative studies were: information about services, support beginning early in their caregiving careers, access to a variety of services and flexibility in how those services are provided, reliable transportation supports, and respite care that provides socialization and stimulation for care recipients, including activities appropriate for their abilities and interests.
Limitations of Studies Reviewed: The authors note that there was a lack of good-quality larger trial studies and that respite interventions studied varied greatly from one another. They noted limited process measures with “poor descriptions of the characteristics of the respite that was provided” and “limited provision and uptake of the respite services that were offered” in the studies. They also noted a lack of economic analyses of respite.

Authors Discussion/Conclusions: Overall, the authors conclude that the implications of their findings for health services are limited. However, they did suggest that a range of respite services is “probably most appropriate” and that such services be responsive to caregivers’ and care recipients’ characteristics and needs and to how their needs change over time.

The authors make several recommendations for future evaluations of respite based on their findings. Foremost, they recommend that before extensive RCT or quasi-experimental comparison studies, developmental work is needed to quantify caregiver needs and preferences, to define the characteristics of an appropriate intervention, and to define and validate respite outcomes for care recipients. The authors recommend that future trial studies measure appropriate short- and long-term outcomes for caregivers and care recipients—including those in ethnic minority groups whose needs may differ. They also highlight a need for economic analyses of respite and recommend that future research address the optimum time point for provision of respite and utilize process evaluation measures. With regard to qualitative research, the authors highlight a need to explore the meaning of a “mental break” for caregivers and how respite interventions can help caregivers achieve this as well as research on how to improve communication of service availability to caregivers.

**Study Aim/Purpose:** The author sought to identify the common findings of quantitative and qualitative studies of respite care for families of children with disabilities.

**Summary of Methods:** A keyword search was conducted to identify studies conducted in the United States, Australia and the United Kingdom. The following electronic databases were searched: Cochrane Database of Systematic Reviews, The Cochrane Clinical Controlled Trials Register, PubMed, PsychInfo, CINAHL, Social Work Abstracts, and the Web of Science. Additionally, the author “checked relevant websites and reference lists of all topic-relevant publications.” The author used the Critical Appraisal Skills Programme system to appraise each article’s methodology. A total of 17 articles were appraised and 15 were considered appropriate for the synthesis.

**Summary of Key Results:** Based on the synthesis of findings from 15 articles, the author highlighted six major findings: 1) family characteristics that appear to influence the use of respite include level of family stress, access to informal support networks, family size, and marital status; 2) use of respite care is associated with significant reductions in parental stress; 3) implementing any form of more structured respite appears to have a positive impact compared to no support or the receipt of standard services; 4) respite offers important short-breaks to families caring for children with multiple disabilities; 5) respite care appears to result in reductions in psychological distress among parents of children with developmental disabilities; and 6) respite care may be considered an intervention for child abuse prevention, especially for those children suffering from challenging behaviors. At the same time, the author notes the lack of research in several important areas including: “the influence of respite care upon the families of disabled children and abuse potential”, “the interrelationships between respite care, child abuse potential, family relations, and parenting stress over time”, and “effective models of respite care for individuals with developmental disabilities and severe behavioral problems.”

**Limitations of Studies Reviewed (as cited by the author):** “Tools used for testing may not have been tested for validity and reliability. There were small sample sizes and samples represented only groups of parents who were specifically seeking certain types of services, and therefore may not have been representative of the larger population of parents of children with developmental disabilities. Some designs did not allow for the assessment of other mediating or moderating variables that could also potentially contribute to child abuse potential.” Additional limitations included 1) no control groups; 2) lack of longer-term follow-up data; and 3) the lack of inclusion of process measures.

**Authors’ Discussion/Conclusions:** The author recommends further research be conducted to assess the impact of respite services including the impacts on child abuse, the impacts specifically for individuals with developmental disabilities and their families, impacts on family members in addition to mothers, and on the longer term benefits of respite care on measures such as stress. She also notes that further research is needed exploring the availability and use of respite care.
Appendix

Expert Panel on Respite Research

Lifespan Respite Technical Assistance Center

ARCH National Respite Network and Resource Center

in collaboration with

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