



Second Edition, 2002

Annotated
Bibliography
of Respite &
Crisis Care
Studies

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Annotated Bibliography of Respite and Crisis Care Studies

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Introduction

For over three decades, planned respite and crisis care programs have been providing temporary relief to caregivers of family members with disabilities or at risk of abuse and neglect. Those of us who are involved in the respite and crisis care movement firmly believe that these programs are of substantial benefit to caregivers and their families. This belief is stated or implied when we advocate for programs, prepare grant proposals, and conduct community outreach and education activities. Whenever possible, we should be prepared to back up our statements of belief with support from the professional literature. This annotated bibliography was prepared as one way of assisting programs to gather documentation that supports the efficacy of respite and crisis care programs.

Although much more has been written on the subject of respite and crisis care, we narrowed our search to articles that focus primarily on research and outcomes. This document contains brief summaries of 38 articles written between 1979 and 2000 and published in professional, peer-reviewed journals. The summaries presented include a complete citation, a brief overview of the article, and quotations that capture some highlights of the text.

If a reader chooses to use some of the quotations found in this document, please appropriately cite the original source of the material. We strongly recommend that you read the complete article so as not to misrepresent the contextual intent of any of the quotations.

Please note that not all of the articles are entirely favorable in terms of providing clear and compelling evidence that respite or crisis care programs achieve certain outcomes. Articles presented describe research that seems to conclude that reductions in family stress, reduced need for out-of-home placements and reduced risk for abuse and neglect can be attributed to respite and/or crisis care programs. Conversely, some articles presented question these conclusions.

McNally, Ben-Shlomo, and Newman's (1999) literature review is a useful overview of the field of respite care studies. The general consensus appears to be that most respite care research studies are methodologically weak and yield inconsistent positive results. Although most of the research articles included in this literature review indicate positive results, they

come with many caveats: some studies did not use control groups, most had quite small samples, and the authors themselves caution against generalizability. Nonetheless, for the respite care field, these summaries should yield useful information, and may lead some organizations to pursue further research.

By printing these summaries, ARCH does not endorse or promote any of the opinions expressed by the authors.

Future Updates

This document should not be viewed as exhaustive or complete. We intend to update it annually and make the updates available to ARCH National Respite Network members. The review was printed so that it could be inserted into a three ring binder and future updates can be added to the binder as they become available.

To assist in the updates, we ask for your help in identifying articles that should be included. If you are aware of any published or unpublished documents (dissertations, theses, etc.) that discuss research or outcome evaluations of respite and crisis care programs, please let us know. Send the ARCH Information Specialist, Yvette Layden, the name of the author, publisher, date of publication and title of the article you would like added to the update. We welcome your suggestions of recently published documents or earlier works that you feel should be included in future literature reviews.

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Abelson, A.G. (1999). Economic consequences and lack of respite care. *Psychological Reports, 85, 880-882.*

This paper describes the influence of the lack of respite care on the careers of parents caring for children with disabilities. A direct correlation was found between the child's severity of disability and parents' work. The greater the child's severity of disability, the more likely it was that parents would miss work or pass up occupational opportunities. As part of an Iowa study on respite care needs, questionnaires were mailed to 2,388 parents of children with a disability. Twenty four percent of the parents responded. The questionnaire included items that examined how work and career patterns are affected by a lack of available and accessible respite care services.

This study's data indicated "a significant association between the age of a child with a disability and parents having refused job opportunities or given up a job to allow more time to care for that child" (p. 881).

"The actual influence of readily available respite services on the careers and job opportunities of parents having children with developmental disabilities is not well documented." (p. 880)

"Data were also presented that showed "a significant relationship between the child's severity of disability and parents having missed more work hours than other employees." (p. 881)

"The more severe the disability, the more likely a parent was to have missed an excessive number of hours at work and refused a job opportunity." (p. 881)

"The lack of available respite care appears to interfere with parents accepting job opportunities." (p. 881)

Note: the authors caution that they did not study whether universal availability and accessibility to respite care would rectify parents' job problems.

Bader, J.E. (1986). Respite care: Temporary relief for caregivers. *Women & Health, 10* (2-3) 39-52

This article reviews some recent respite care research, and describes the advantages and disadvantages of respite and home-based care. This is a descriptive article, not a research article. It describes the typical elderly patient and the caregivers, citing that the primary beneficiaries of respite care are the caregivers.

The authors describe the “enormous costs—and risks—to the caregiver of maintaining mentally and/or physically disabled family members at home” (p. 43).

One risk of *not* having respite care available is the potential of the patient being committed to an institution. “...failure to adequately accomplish one’s ‘activities of daily living’ (ADLs) is likely to cause the public to commit a person to an institution faster than the fact that their behavior is eccentric or bizarre” (p. 44).

“Should the caregiver’s physical and emotional health deteriorate, taxpayers may be asked to pick up the costs of care for the caregiver as well as the patient. Such hidden long-term costs have not yet been demonstrated because the longitudinal research necessary to examine such long term societal costs has not yet been done.” (p. 43)

“A third cost for the caregiver is economic. Prolonged care-giving, whether at home, or elsewhere, is expensive....It is precisely because of the economic realities of aging that some attorneys recommend that caregivers divorce their spouses in order to preserve at least a portion of their incomes for living expenses. Failure to do so, they say, may result in financial ruin, especially for aging women.” (p. 43)

“...respite care may prove to be an inexpensive investment in the quality of care for all elders in need and in the prevention of ‘burn-out’ among most caregivers.” (p. 44)

“Although a relatively recent development, respite care has been modestly supported by Medicaid and various state governments largely because it is believed to be a low cost way to keep chronically impaired persons out of costly institutions and because it is believed to be a low cost investment in the health of caregivers.” (p. 46)

“It may be more cost-effective to invest in caregivers’ physical, financial, and emotional well-being than to provide the care required when caregivers become ‘patients.’” (p. 41)

Berry, G. L., Zarit, S. H. & Rabatin, V. X. (1991). Caregiver activity on respite and nonrespite days: a comparison of two service approaches. *Gerontologist*, 31, (6), 830-835.

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Examined the use of time among caregivers of dementia patients who used respite services. Participants included 40 female caregivers aged 51-74, 20 of whom used home care and 20 of whom used day care respite services. Caregivers reported on their current situations and on six occasions were administered a modified version of the Yesterday Interview. This instrument is a detailed time budget used to elicit, chronologically, the activities an individual performed the previous day, time spent on each activity, the location of each activity, and the social context of each activity. Activity information was collected on 3 days when home care or adult day care services were used and on 3 days when there was no service use. Differences between users of day care and in-home respite care were found for the ratings of life satisfaction, the quality of the caregiver/care receiver relationship, and time spent away from the care receiver. On days when respite services were used, large blocks of freed time provided a break from care demands and the opportunity to spend time away from the care receiver and to engage in noncaregiving activities. However, respite's capacity to reduce caregiving time was apparent only for the home care users. In fact, women who used day care services spent more time performing caregiving activities on respite days than they did on nonrespite days. The free time provided by respite was mostly spent working or catching up on household chores, as opposed to resting or engaging in family or social activities. (WD) (Ageline Database, copyright 1991 AARP, all rights reserved.)

“On days when respite services were used, large blocks of freed time provided a break from care demands and the opportunity to spend time away from the care receiver and to engage in noncaregiving activities.” (p. 834)

“...respite's capacity to reduce caregiving time was apparent only for the home care users. In fact, women who used day care services spent more time performing caregiving activities on respite days than they did on nonrespite days.” (p. 834)

“In short, respite provides relief from care demands and frees blocks of time to engage in other activities, but it does not necessarily reduce the amount of time spent on caregiving.” (p. 834)

“The free time provided by respite was mostly spent working or catching up on household chores, as opposed to resting or engaging in family or social activities. These

Berry, G. L., Zarit, S. H. & Rabatin, V. X. (1991). Caregiver activity on respite and nonrespite days: a comparison of two service approaches. *Gerontologist*, 31, (6), 830-835. (continued)

findings suggest that respite might be most effective for those caregivers with specific, competing responsibilities such as work or family, and most helpful to those caregivers who are neither frail nor overwhelmed by continuous caregiving. More specifically, the data suggest that respite might be most effective when the caregiver's need is for a block of planned, uninterrupted time to engage in activities necessary to run a household (i.e. work, household chores, etc.) or for relief from continuous caregiving activities. However, when the gain of respite is being offset because of the time the caregiver spends preparing and delivering the patient to day care, then disincentives to service use may exist." (p. 834)

"Determining the need and timing of respite, educating the caregiver about respite and use of free time, and continued follow-up are the dynamics of service delivery that are often overlooked in service effectiveness. In other words, respite is not a single service but a 'service package' that includes assessment of need, education, respite, and follow-up." (p. 834)

Boise, L., Heagerty, B., & Eskenazi, L. (1996). Facing chronic illness: The family support model and its benefits. *Patient Education and Counseling*, 27, 75-84.

A hospital-based program that provides information, education, support, and respite services is described. While this article is not focused solely on respite care, a few interesting points are applicable to respite care. The information presented in this article would be more useful for respite programs that also have an educational component.

The authors summarize a 1986 study (Vickery D., Kalmer H., Lowrey D., Constantine M., Wright E., & Loren W.): “a randomized, controlled trial of self-care educational interventions reduced total medical visits and minor illness visits by 17% and 35% respectively. Self-care education programs can decrease medical visits, especially for minor illnesses” (p. 82).

“Contrary to popular belief, Americans do not abandon their elderly or chronically ill relatives. Studies of informal care giving consistently indicate that 75-80% of care is provided by family members and other informal providers, suggesting that the medical care system is dependent on both selfcare by the patient and care provided by families to achieve optimum well-being for individuals with chronic illness.” (p. 75)

“The danger is not that families will abandon their ill relatives but that the health care system will abandon its care-givers.” (p. 75)

“The programs described in this article can have important beneficial effects on health services utilization and costs. To a very real extent, the medical care system is dependent on both self-care by the patient and care provided by the family to achieve optimum well being for individuals with chronic illness, cognitive impairment, or functional disability. Research shows that emotional factors such as anxiety and depression increase the number of visits to physicians. Research shows that only between 12 and 25% of medical care utilization can be explained by objective disability or morbidity alone.” (p. 81)

Citation referred to in the annotations above and cited with the article's references:

Vickery D., Kalmer H., Lowrey D., Constantine M., Wright E., & Loren W., Effect of a selfcare education program that reduces out-patient visits. *Journal of American Medical Association*, 1986 250:2952-2956

Boothroyd, R.A., Kuppinger, A.D., Evans, M.E., Armstrong, M.I., & Radigan, M. (1996). Understanding respite care use by families of children receiving short-term, in-home psychiatric emergency services. *Journal of Family Studies*, 7, (3), 353-376.

This article reports the findings of a respite care utilization study. The study was a component of a larger study looking at a variety of services for children experiencing psychiatric crisis. Three models of intensive, in-home services are described. Of the 146 families eligible to receive respite services, only 34% of the families actually used any type of respite care. This utilization was lower than estimates made prior to the study.

Patterns of respite care utilization were investigated, as were the characteristics of the families and children who used or did not use respite care.

In their introduction and literature review, the authors note that, “The extent of research on respite care use by the families of children with SED (serious emotional disturbances) is insufficient to comment confidently on its effectiveness.” (p. 354)

Interviews indicated that many caregivers did not understand what it meant to receive respite care or even that it was available to them. Respite care users were more likely than non-respite care users to have:

1. Younger children,
2. Children with a greater number of impairments,
3. Few social supports, and
4. Greater difficulty managing their children’s difficult behaviors.

The authors found that 89.5% of families who used respite care were satisfied with the services they received, and that 89.5% felt the worker was someone their child liked, who could manage their child’s behavior (73.7%), and who provided a safe environment (78.9%). These elements “ranked fairly high in the caregiver’s list of ‘what matters’” (p. 366).

Caregivers were “adamant that it (respite care) provided families with an essential support that benefited both child and caregiver” (p. 370).

The authors cite a study conducted by Bruns & Sturdivant,* (1996), that investigated the impact of respite care utilization on the use of out-of-home placement days, caregiver stress, family functioning, and child behavior. “On average, families who received respite care used fewer out-of-home placement days, and experienced reduced personal strain” (p. 354).

Boothroyd, R.A., Kuppinger, A.D., Evans, M.E., Armstrong, M.I., & Radigan, M. (1996). Understanding respite care use by families of children receiving short-term, in-home psychiatric emergency services. *Journal of Family Studies*, 7, (3), 353-376. (continued)

“In this study we found families who used respite care services reported significantly fewer social supports than did families who did not use respite care.” (p. 372)

“...the availability of respite care within the context of short-term emergency programs seems warranted given the stress of caregivers coping with a child experiencing a psychiatric crisis, particularly those who are isolated and have no place to turn.” (p. 372)

“In-home respite care was preferred by caregivers, provided greater flexibility, was less restrictive and costly, and a more palatable alternative for many caregivers, since out-of-home respite care was frequently perceived as the first step of having their child removed from the home.” (p. 373)

Citation referred to in the annotations above and cited with the article's references:

*Bruns, E.J. & Sturdivant, J. (1996, April). Impact of respite care services on children experiencing emotional and behavioral disturbance and their families. Paper presented at the Building Family Strengths Conference, Portland, OR.

Botuck, S., & Winsberg, B.G. (1991). Effects of respite on mothers of school-age and adult children with severe disabilities. *Mental Retardation*, 29, (1), 43-47.

Fourteen mothers in this study participated in a pre-planned, 10-day overnight respite. Subjects were mothers of children who were non-ambulatory and had profound or severe mental retardation and cerebral palsy. Changes in mood, well-being, and activity patterns was measured before, during and after respite. The benefits of respite persisted for at least 3 to 4 days after the child's return. Caregivers experienced positive changes in their activity patterns, with increasing time spent in ways that helped their personal mental health.

“During this respite, mothers experienced ‘increased feelings of well-being and less depressed mood’ and these changes continued after respite.” (p. 45)

“...mothers were ‘happier’ (*i.e.*, increased feelings of well-being and less depressed mood) during respite than they were either before or after respite.” (p. 45)

Braithwaite, V. (1998). Institutional respite care: Breaking chores or breaking social bonds? *The Gerontologist*, 38, (5), 610-617.

Note: Article was received electronically; page numbers for quotations unavailable.

This article examined why respite is not more widely used by those who are deemed to need it when most caregivers evaluate respite so positively. This study used data gathered from interviews with 144 caregivers of dependant adults in Canberra, Australia, as the basis for examining respite care usage.

The author found that “use of respite care is higher when the task demands of care-giving are high, and when caregivers and care receivers are bound together in dysfunctional care-giving relationships.”

“Caregivers sharing close intimate relationships with their care receivers may put the interests of the other ahead of their own in considering future use (of respite care). In cases where the relationship is not supportive and intimate, caregivers may be more likely to opt for the opposite strategy, risk straining the social bond, and take the break that respite care offers.”

“Through two decades of debate and uncertainty over the effectiveness of programs for caregivers, two findings have held firm. First, caregivers are satisfied, for the most part, with support programs and ask that more be available. Second, services often are not utilized fully, with many elders regarded as most in need not taking advantage of the opportunities available.”

“Respite care can be beneficial in delaying institutionalization.”

“The findings of the present study raise concerns about whether the strength of the social bond between caregiver and care receiver has been underestimated in planning for formal support for informal care. Love and the expectations that go with it do not disappear when caregivers become overloaded with demands from their care receivers. How they decide to deal with their distressing situation is not going to mirror the decision process of the disinterested policy analyst who relies on rational calculations of unmet needs and resources available. As long as a significant proportion of care in our society takes place within intimate relationships, shared understandings, empathy, timing, and trust between caregiver and care receiver will be critical elements in determining when respite care can be used beneficially and when it cannot.”

Bruns, E.J.& Bujrchar, J.D. (2000) Impact of Respite Care Services for Families With Children Experiencing Emotional and Behavioral Problems. *Children's Services: Social Policy, Research, and Practice*, 3(1), 39-61.

Seventy-three Vermont families with children experiencing emotional and behavioral disturbance (EBD) participated in a controlled study of the short-term effectiveness of respite. The study involved three groups of families; a respite group made up of 33 families who received at least 50 hours of respite in a 6 month period, a control group comprised of 28 families on the wait list for respite services, and a third group of families who received between 1 and 49 hours of respite. Results indicated that moderate amounts of respite are beneficial for families with children with EBD. The respite group experienced “significantly better outcomes overall than did 28 families in a wait-list comparison group, including fewer incidents of out-of-home-placements, greater optimism about caring for the child at home, reductions in some areas of caregiver stress, and fewer incidents of negative behaviors expressed in the community (page39).”

“In program descriptions and research literature, *respite care* has been defined as ‘the provision of temporary care to persons with disabilities, with the primary purpose of providing relief to caregivers (Warren & Cohen, 1985, p.66). Although this definition describes benefits to the caregiver, respite is generally described as benefiting the entire family (Rivera & Kutash, 1994). In addition to the break received by parents, the child is hoped to receive a positive social experience, and the child’s siblings may engage in more interaction with parents.” (p. 40)

“Families in the RG [Respite Group] experienced outcomes statistically superior ($p < .05$) to CG [Control Group] families for two variables: use of OHP [out of home placement] and the personal strain of caregiving as measured by the IOFs.” (p.57)

“Perhaps the most encouraging outcomes associated with respite was the reduction in the percentage of families using OHP and the reduction in OHP days required. These findings, combined with RG caregivers’ greater optimism about caring for the child at home in the future, represent a consistent indication of respite’s potential as a preventative family support service.”(p.57)

“The most striking outcome related to OHP was the impact of respite on families who had utilized OHP in the 6 months before being referred to the respite program. Five such families received respite shortly after being referred, and 6 months later, none of the 5 families had been forced to place their child out of the home. In contrast, 8 families who

Bruns, E.J.& Bujrcharad, J.D. (2000) Impact of Respite Care Services for Families With Children Experiencing Emotional and Behavioral Problems. *Children's Services: Social Policy, Research, and Practice*, 3(1), 39-61. (continued)

recently experienced OHP were placed on waiting lists, and within 6 months, 6 of those families (75%) had used OHP” (p.58)

“...these results suggest that respite’s most potent application may be in the prevention of further OHP days for families who are caring for a child returning home.” (p.58)

“Results of a series of hierarchical regression analyses suggested that increased respite allocation was associated with improved outcomes for families. Specifically, increased respite allocation was most significantly associated with increased optimism about caring for the child at home, elevated family functioning, and reduction in perceived stresses.”(pp.58-59)

“Despite the challenges faced by the families in the sample, goals of reducing incidence of OHP appeared to be met, especially for families who recently had a child return home from a placement, and there also were associations between receipt of respite and positive intermediate outcomes.” (p.59)

Citations referred to in the annotation above and cited with the article’s references:

Warren, R., & Cohen, S. (1985). Respite care. *Rehabilitation Literature*, 46, 66-71.

Rivera, V.R., & Kutash, K. (1994). *Components of a system of care: What does the research say?* Tampa: Florida Mental Health Institute, University of South Florida, Research and Training Center for Children’s Mental Health.

Cacioppo, B., & Andrews, S. (1979). Respite care for parents of handicapped children: A pilot project. *Social Work in Health Care*, 5, (1), 97-101.

This paper describes a respite care program developed for families with children who are handicapped. The respite care consisted primarily of trained babysitters, and the article describes the curriculum for training the babysitters, recruitment, and linking the consumers with this resource. The article is weak on outcomes. According to the authors, many parents returned unanswered questionnaires.

“Within a short time [of newspaper publicity about the trained baby sitters] the number of individuals wanting similar training exceeded the original applicants. Parent requests flooded the office. ‘Could the sitters care for my 18 year old mentally retarded son?’ ‘Could they handle my emotionally disturbed child?’ ‘How about caring for my wife who is a stroke victim?’ ‘We live on a farm and are going on vacation. Can someone watch our 41-year-old retarded son and the farm?’ “(p. 99)

“Good babysitters for handicapped children are a major need of the parents. Families also need longer respite periods such as weekends and one-to two weeks in order to get away for a vacation.” (p.100)

Campbell, H. (1996). Inter-agency assessment of respite care needs of families of children with special needs in Fife. *Public Health*, 110, 151-155.

This article describes a mail questionnaire survey of caregivers of children with special medical needs conducted in Fife, Scotland. The survey identified patterns of respite care use as well as their attitudes about institution-based respite care available to them in the local hospital. The results indicated that there was not only a significant demand for additional respite, but depending on families' specific needs, a variety of types of respite care should be offered.

The authors suggest that although the children have special medical needs, a hospital is not an appropriate setting for respite care. They also suggest that more resources are needed for these children.

The parents expressed concerns about "...the difficulties of obtaining access to these services (particularly in times of emergency to allow them to cope with sudden unexpected demands placed on their family)" (p. 154).

"Appropriate respite care can help prevent some of the family morbidity (marital disharmony, depression, exhaustion and behavioral disorders in siblings) associated with the care of these children and may make a positive contribution to the quality of life of the child." (p. 154)

Selected comments of parents on their need for respite care services:

"Respite assistance with older children is more essential than that with young children since parents are older and less able to cope, whilst children become heavier and stronger and so more difficult to manage." (p. 153)

"Respite care gives parents the chance to re-charge batteries and keep stress levels from exploding." (p. 153)

Chang, J.I., Karuza, J., Katz, P.R., & Klingensmith, K. (1992). Patient outcomes in hospital-based respite: A study of potential risks and benefits. *Journal of the American Board of Family Practice*, 5, 475-481.

This article, unlike most, focuses on the benefits of respite to the patient — namely, how hospital-based respite impacts the patient. The patients studied were elderly and had chronic disabilities. During an average respite stay of 15 days, the patients did not experience increased risk of illness from being in the hospital. Benefits at 6 months included fewer admissions for acute medical care for the respite group (than for two control groups). The total number of hospital days was roughly equal for the respite group and the community-based control group, but was fewer than that for the acute care control group.

The authors note: “our results do not indicate any harm and (we) argue that a slight benefit is associated with hospital-based respite” (p. 479).

“Because of potential complications that can develop for chronically ill geriatric patients, a hospital setting for respite care can be a viable respite alternative. A valid concern for physicians, however, remains the potential danger of a greater rate of iatrogenic illness and expectation of more aggressive care based on a tertiary care model.” (p. 475)

“Currently 4.8 million of the 6.6 million older adults who require long-term care receive this care in the community from their families.” (p. 475)

“With the growing bulge of adults older than 85 years, who have a much higher number of chronic conditions and disabilities, the burden on family caregivers will expand as they are required to provide more intensive care.” (p.475)

“The major benefit associated with respite was the reduction in the number of acute hospitalizations in the respite patients.” (p. 480)

Chi, I. & Wong, S. F. (1994). Respite service for the elderly in Hong Kong: evaluation of a pilot project. *Journal of Gerontological Social Work*, 22, (3/4), 201-210.

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Evaluates a pilot respite service program for caregivers of elderly patients in Hong Kong. Established in March 1989, the service aimed to provide caregivers of the elderly with temporary relief from their caring burden to avoid premature institutionalization of the elderly patient. The service was operated in hostels that served elderly who were capable of self-care and in homes for those in frail health with limited self-care abilities. An evaluation of the program was carried out from March 1989 to February 1990. Data were collected from the elderly clients and their principle caregivers through an interview prior to using the service and follow-up telephone interviews conducted by a research assistant for both groups one month after the clients returned home. A total of 43 elderly clients and the same number of their principal caregivers participated in the study. Nearly 70 percent of the elderly clients were female, while the average age was 78.3 with a majority aged 75 and over. Twenty-seven percent were married, of whom 59 percent were widowed. The majority of caregivers were female, and the average age was 50.2, with 25.6 percent of caregivers aged 60 and over. Close to 75 percent of caregivers lived with the elderly clients, one-fourth were spouses, and over 65 percent were children or in-laws. Analysis indicated that the average utilization rate of the service was low, and a seasonal fluctuation existed, with higher use rates during the summer. A total of 93 percent of the principal caregivers were satisfied with the service, and 76 percent of them would consider re-using the services. Nearly half of the caregivers who had previously considered institutionalization had changed their minds after using the respite services. Caregivers' and elderly clients' attitudes toward the caring relationship after using the services are presented. (TS) (*Ageline Database, copyright 1991 AARP, all rights reserved.*)

Cockerill, R. & Warren, S. (1990). Care for Caregivers: The Needs of Family Members of MS Patients. *Journal of Rehabilitation*, 41-44.

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Support for caregivers is currently an important concern of health professionals: however, while the physical, emotional, and financial costs of providing care have been documented, there has been less attention spent on the respite options available for caregivers. This study examined the experiences and needs of caregivers of individuals with multiple sclerosis and concluded that caregivers are underutilizing available respite services and feel uncomfortable with the options available to them. Further research needs to explore the reasons for underutilization of respite services and, with this information, develop ways of ensuring caregivers know about these options and feel comfortable using them.

“Health and social science professionals, social science researchers and legislative policy makers are recognizing that family caregivers represent a tremendous resource and that without their dedication, a much greater percentage of chronically ill patients would require institutionalization.” (p. 41)

“Low utilization of respite services may mean that caregivers are not aware of the options available to them.” (p. 44)

“Support for caregivers is currently an important concern of policy makers and social science and health professionals, since it appears vital to preventing institutionalization. Numerous researchers have concluded that if family members are to continue caring for ill relatives, then community and government support services must share the burden and help to reduce their strain and morbidity.” (p. 44)

“More attention needs to be paid to the reasons for underutilization of already existing services.” (p. 44)

“In sum, while it is clear that respite is needed, what is also needed is a way to ensure family members know about these options and feel comfortable using them. It may be that options such as educational programs, support groups, or possibly even greater information through mechanisms such as newsletters are needed to educate the caregivers that they can, and should, receive some assistance with their caregiving duties.” (p. 44)

Cowen, P.S. (1998). Crisis childcare: An intervention for at-risk families. *Issues in Comprehensive Pediatric Nursing, 21, 147-158.*

This study examines the relationship between parent stress and the use of Crisis Care services. The Parenting Stress Index/Short Form (PSI/SF) was used to measure the amount of stress experienced by the parent as a result of the parenting role. Comparisons of pretest and posttest scores indicated significant improvement in the areas of Total Stress, Parental Distress, Difficult Child, and Life Stress. In addition, compared with counties that did not offer crisis care intervention, there was a significant decrease in child maltreatment reported in the rural counties that offered a crisis childcare program. The research indicated that crisis care for children is effective as a preventive intervention for families at-risk of abuse and neglect.

The study examined 515 children from 240 families who were enrolled in the crisis child care programs in four rural Iowa counties. Families could have 30 days of crisis child care per year. The provocation for admission to the program included parent illness or accident, suspected/actual child maltreatment, need for support, and domestic violence.

“At their most basic level, (respite and crisis child care programs) provide parents in crisis with a break from the stresses of childrearing. A variety of research studies have consistently found parenting stress to be a significant precipitating factor in child maltreatment.” (p. 147)

“The long-term positive outcomes for children who have received crisis care services are threefold: (1) remediation of developmental lags and deficits, (2) improvement in self-esteem and self-confidence, and (3) enhanced coping skills for the stress in their lives [as found in Beezley et al., 1976].” (p. 148)

“The results of this study support the conclusion that crisis child care programs provide useful and effective services that are important in the prevention of child maltreatment.” (p.157)

Citations referred to in the annotations above and cited with the article's references:

Beezley, P., Martin, H., & Alexander, H., (1976). Comprehensive family oriented therapy. In R. Helfer & C. Henry Kempe (Eds.), *Child abuse and neglect: The family and community*, (pp. 169-195). Cambridge, England: Ballinger Publishing Co.

Cox, C. (1998). The experience of respite: Meeting the needs of African American and white caregivers in a statewide program. *Journal of Gerontological Social Work*, 30, 59-72.

This study examines two groups of individuals caring for their relatives with Alzheimer's disease. Two hundred twenty eight (228) African American and white caregivers were interviewed. Each caregiver was seeking respite care. A comparison of the effects of respite on the caregivers was made after they had received respite for six months. The findings indicate that white caregivers experienced less gain from the respite experience than the African American group.

“Both groups reported significant reductions in their feelings of burden. Exhaustion declined among the African Americans” (p. 67). However, white caregivers' satisfaction with their informal support networks dramatically increased with the use of respite. “Consequently, the service may help to relieve the pressure on the informal system and improve relationships” (p. 69).

“It is particularly noteworthy that the behavior of the African American patients significantly improved with respite. Reasons for this change are not clear but one possible explanation is that with the assistance, African American caregivers felt better able to cope with the patient and deal with any erratic behavior. Since behavioral problems are a major source of stress and are frequent precursors of institutionalization, further research which examines the ways in which respite may be associated with behavioral changes could be helpful in the development of future programs.” (p. 70)

Deimling, G. T. (1991). Respite Use and Caregiver Well-Being in Families Caring for Stable and Declining AD Patients. *Journal of Gerontological Social Work*, 18, (1-2), 117-134. Reprinted with permission of Ageline.

Studied the relationship between respite use and caregiver well-being in families caring for stable and declining Alzheimer's disease (AD) patients. Interviews were conducted with 78 family caregivers to AD patients on two occasions: upon entrance into the Time Off Promotes Strength (TOPS) respite program, and 4-6 months after the start of service. Four measures examined the impact of respite on caregiver well-being: the CES-D scale, an index of self-reported health problems, an instrument measuring caregiver strain, and reports on activity restrictions resulting from caregiving responsibilities. Stability or decline in the AD patient's functioning was documented with a measure of impairment in activities of daily living (ADL) and an indicator of cognition. Stable patients (59 percent) were those whose ADL competency scores increased or remained the same between assessment and follow-up; 62 percent were stable in terms of cognitive impairment. In most cases, declines were small. Analysis indicated that respite use reduced depression, health problems, and relationship strain in families caring for stable AD patients, although it did not decrease caregiver activity restrictions. Among families in which the AD patient was declining cognitively, respite was not able to stabilize caregiver strain, and caregiver health problems and relationship strain increased. It is suggested that the emotional strain of watching a family member decline in such a way may not be alleviated by respite care, and counseling or support group participation may be more appropriate. (UH) (*Ageline Database, copyright 1991 AARP, all rights reserved.*)

"...study findings suggest respite may have a beneficial impact. One impact is to stabilize the strain and well-being of caregivers in situations where the AD patient is declining. Additionally, at least in terms of depression, health problems and relationship strain, respite may well benefit caregivers in those families where the elder's condition is relatively stable. Moreover, the AD patients in these families did not appear to either benefit or suffer adversely from participation in the program. In conclusion, this research was able to document when caregivers benefit from respite and when respite does not seem to be able to achieve its intended effects." (p. 132)

"The fact that this research documented the differential impact of respite depending on the AD patients' characteristics also is important because it suggests that practitioners need to have realistic expectations about what respite can and cannot do for whom. Respite as a periodic, temporary service is not a substitute for more comprehensive forms of long-term care services." (p. 133)

Dorfman, R.A. (1996). Cost-free resorts for the elderly? Hong Kong's Cheung Muk Tau Holiday Centre. *Journal of Gerontological Social Work*, 26, 171-178.

This is an unusual program, perhaps unique in the entire world. Hong Kong offers a state-subsidized virtually cost-free two-day resort vacation to all elderly Hong Kong residents. The purpose is to improve the relationships between older adults and their family members and to provide temporary respite for caregivers. Elders are allowed at certain times to invite family members to the resort with them. The resort hosts several activities and special events catering to the needs and interests of the elders. Respite care for up to two weeks is also available.

The research findings indicate that “elder abuse is less likely to be experienced among those elderly who are actively involved in social activities” (p. 176).

Dziegielewski, S. F. & R., J. L. (2000). Adult day programs for elderly who are mentally impaired and the measurement of caregiver satisfaction. *Activities, Adaptation and Aging*, 24, (4), 51-64.

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Examined whether an adult day program that specializes in helping those afflicted with dementia can serve as an effective way of providing respite care to caregivers. Twenty-six caregivers aged 34 and older (mean age 62) of persons with dementia who were participating in a dementia adult day program responded to mailed surveys eliciting information about demographic characteristics, amount of time the care receiver had been in day care, relationship of the caregiver to the care receiver, length of time as a caregiver, and caregiver feelings about and satisfaction with the day program. Results indicate that day care alone did not offer a complete form of respite to the caregiver; however, overall caregiver satisfaction was strong, and the day program was viewed as a positive way to provide partial respite to caregivers. It is concluded that there is a need for expanding development of comprehensive adult day services for persons with dementia and their families. Counseling and other additional supportive services for the caregiver need to be considered to make the day services a more inclusive form of respite. (KM) (*Ageline Database, copyright 2000 AARP, all rights reserved.*)

Evans, M.E., & Armstrong, M.I. (1994). Development And Evaluation Of Treatment Foster Care And Family-Centered Intensive Case Management In New York. Journal of Emotional & Behavioral Disorders, Vol. 2, Issue 4, p228.

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In response to a national call for states to shift from an overreliance on restrictive treatment modalities to community-based systems of care and to the needs identified by the families of children with serious emotional disturbance (SED), the New York State Office of Mental Health has developed Family-Centered Intensive Case Management (FCICM) as part of a research demonstration project. FCICM is intended to empower and support families with children with SED. Staffed by a case manager and parent advocate, FCICM includes respite care, flexible service money, parent support groups, and behavior management skills training. In this study, which had positively controlled experimental conditions, children who were referred for treatment foster care in three rural New York counties were randomly assigned to FCICM or treatment foster care. The present article compares and contrasts the program elements of FCICM and the treatment foster care models, provides an overview of the research design and methods, describes the children and families served, and examines program implementation issues.

“Over the past 15 years, a number of national studies on children’s mental health services have concluded that major changes need to be made in how services are planned for, provided to, and delivered to children and adolescents with serious emotional disturbance (SED) and their families.”

“The New York State Office of Mental Health (the state mental health authority) is guided by a set of core principles in the development and delivery of services to children and their families, one of which is that the family is the most desirable setting in which to raise children and that clinical practice, policy direction, and funding must support the rearing of children in family and family-like settings (New York State Office of Mental Health, 1992). These principles were operationalized by the establishment of community-based services such as treatment foster care, psychiatric emergency services, and intensive case management programs that were child centered and family focused. Although these programs were positively received by providers and parents, early experiences convinced policymakers that a number of additional individualized supports (e.g., respite and peer support groups) would be necessary if children were to remain in family settings.”

Evans, M.E., & Armstrong, M.I. (1994). Development and Evaluation of Treatment Foster Care and Family-Centered Intensive Case Management in New York. *Journal of Emotional & Behavioral Disorders*, Vol. 2, Issue 4, p. 228.

(continued)

“At enrollment, unmet service needs for children were reported to be greatest in the areas of recreation (n=30, 79%), mental health (n=20, 51%), education (n=15, 38%), dental (n=13, 33%), and medical (n=9, 23%). In the mental health area, the greatest need was reported for respite care (n=14, 36%). Clinic services (n=13, 33%), adjustment to daily living skills training (n=13, 33%), psychotropic medication management (n=3, 8%), and day treatment (n=1, 3%) were also identified as needed.”

“FCICM parents expressed a preference for in-home respite, and the program model was amended accordingly. In-home respite providers were recruited for their experience working with children and adolescents with special needs. When necessary, respite care was also provided for siblings of enrolled children.”

Citations referred to in the annotations above and cited with the article’s references:

Donner, R. (1988). Rest-a-bit: Respite care training project. Topeka, KS: Families Together, Inc.

New York State Office of Mental Health (1992). *At the crossroads: Expanding community-based care for children and families*. The New York State plan for children and families mental health services. Albany: New York State Office of Mental Health, Bureau of Children and Families and the Bureau of Planning, Assistance and Coordination.

Feinberg, L. F. & Whitlach, C. J. (1997). Family Caregivers and Consumer Choice: Options for In-Home Respite Care. *Family Caregiver Alliance*.

Note: Article was received electronically; page numbers for quotations unavailable. (Used with permission of Family Caregiver Alliance/National Center on Caregiving. www.caregiver.org)

An emerging trend in the delivery of quality and cost-effective home and community-based long-term care is the movement toward “consumer-directed services.” The concept of consumer direction implies that consumers prefer to make decisions about their service needs and are able to take a more active role in managing their own services. However, there is relatively little research which examines preferences for, or outcomes of, consumer-directed versus professionally-managed home and community-based care. The studies that do exist focus largely on younger adults with physical disabilities who use personal assistance services delivered through either agency-based or “independent providers.” In contrast, few studies have focused on the choice and preferences of family caregivers of persons with cognitive impairments in general, and the delivery of in-home respite care, in particular. Yet the question of how to deliver high quality, cost-effective in-home respite services which are responsive to family needs and desires is a growing policy issue in long-term care for those designing and testing services interventions for family caregivers.

The one-year study described in this report examined the in-home respite experience of family caregivers served by California’s model system of Caregiver Resource Centers (CRCs). While California’s CRCs offer families a broad range of support services and respite options (e.g., in-home care, adult day services, weekend respite camps), in-home respite is usually the caregiver’s first choice when considering various respite options. In-home respite care is delivered through two mechanisms: (1) the vendor in-home respite program (i.e., agency-based) in which caregivers are given vouchers to purchase service hours from home care agencies under subcontract with the CRC; or (2) the “direct pay” respite program whereby caregivers are given vouchers to hire and manage their own respite workers. The direct pay respite program (also commonly known as the “independent provider” model) is considered a consumer-directed mode of service delivery.

The main purpose of the study was to examine the reasons why caregivers use different modes of in-home respite, the characteristics of these caregivers, their satisfaction with services and quality of care, and the related utilization and cost issues of providing in-home respite care for family caregivers. Understanding the California experience is important for advancing our understanding of cost-effective ways of organizing and delivering services to

Feinberg, L. F. & Whitlach, C. J. (1997). Family Caregivers and Consumer Choice: Options for In-Home Respite Care. *Family Caregiver Alliance*. (continued)

the growing number of families caring for loved ones at home with dementing illnesses and other cognitive impairments.

Key findings of the study included...”Caregivers overwhelmingly preferred direct pay respite (68.5%) to agency-based respite”...”Direct pay caregivers were mostly caring for relatives who had suffered a stroke (32.8%) and agency-based users were mostly caring for a relative with Alzheimer’s disease (33.3%)”...”In both groups, family caregivers were predominantly wives who had been providing care for an average of more than nine years.”

There were multiple reasons caregivers chose one type of in-home care over others. “Caregivers in both groups reported the same top two reasons for preferring their respective mode of in-home respite: wanting to be sure their loved one was safe (91.3% direct pay and 84.6% agency-based); and having good, reliable and trustworthy help (87.8% direct pay and 94.2% agency-based).”

“Concern for safety was valued the most by the caregivers: When asked what was the ‘single most important reason’ for choosing the type of in-home respite they received, more than four out of ten caregivers in both groups said the safety of their loved one was the most important reason. “

“While wanting the most service for the lowest cost was important for a little over half of both groups, overall, safety concerns and reliable and trustworthy help were more important to caregivers than cost issues and hours of care.”

Flint, A. J. (1995). Effects of respite care on patients with dementia and their caregivers. *International Psychogeriatrics*, 7, (4), 505-517.

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Reviews the literature on the effects of formal respite care for patients with dementia and their caregivers. A computerized search of three databases (MEDLINE, PsycINFO, and CINAHL) for relevant English-language articles published from 1975 to 1994, using the key words “respite care” with “dementia,” “Alzheimer’s disease,” and “multi-infarct dementia,” yielded 58 articles; an additional 22 papers were obtained through the review of bibliographies. Five studies met the following inclusion criteria: original research, controlled trial of a defined respite intervention, sample including a dementia population, and at least one outcome measure relating to at least one of eight variables (caregiver burden and stress, psychiatric status of caregiver, physical health of caregiver, and attitude toward patient; cognition, behavior, and physical health of the patient; and rate of institutionalization). Four studies met validity criteria and were included in the review: Burdz and colleagues (1988), Conlin and colleagues (1992), Lawton and colleagues (1989), and Mohide and colleagues (1990). Little evidence was found to show that formal respite care has a significant effect on caregivers’ burden, psychiatric status, or physical health; or on patients’ cognition, function, physical health, or rate of institutionalization. However, given the small number of controlled studies found and their methodological and conceptual limitations, these data should be interpreted with caution. (SW) (*Ageline Database, copyright 1996 AARP, all rights reserved.*)

“Respite care did not have a significant effect on burden for caregivers of demented or nondemented subjects. However, there was a statistically significant improvement in problematic behavior ($p < .001$) for both demented and nondemented patients in the respite group.” (p. 507)

“There were no statistically significant differences between the treatment and control groups in caregiver stress scores at any assessment point.” (p. 510)

“Based on the results of these controlled studies, there is little evidence that formal respite care has a statistically significant impact on caregivers’ burden, psychiatric state, or physical health, although one study (Mohide et al., 1990) did find a clinically significant improvement in their quality of life.” (p. 512)

“Burdz and colleagues (1988) did not find that 2 weeks of institutional respite had a significant impact on patient’s cognition; also, they found, behavior improved.” (p. 514)

Flint, A. J. (1995). Effects of respite care on patients with dementia and their caregivers. *International Psychogeriatrics*, 7, (4), 505-517. (continued)

“Based on the results of controlled studies, there is little evidence that respite care for a patient with dementia significantly affects caregiver burden or delays institutionalization of the patient. In fact, there is some suggestion from uncontrolled trials that utilizing respite services may increase the rate of institutionalization. However, given a small number of studies and methodological and conceptual problems these data are far from conclusive, and benefits of respite care might be demonstrated in the future through better-designed trials. Paradoxically, this lack of documented efficacy stands in contrast with many caregivers’ reports of high levels of satisfaction with respite services (Adler, 1992; Lawton et al., 1989; Pearson, 1988). There are many reasons caregivers choose respite care. To the extent that it gives them time off to have a rest or attend to noncaregiving activities, respite care is a success, and it is not surprising that, from this point of view, caregivers would rate it highly.” (p. 515-516)

Citations referred to in the annotations above and cited with the article’s references:

Adler, G. (1992, March/April). Dementia caregivers: Expectations of respite care. *American Journal of Alzheimer’s Disease and Related Disorders and Research*, 8-12.

Burdz, M.P., Eaton, W.O., & Bond, J.B. (1988). Effect of respite care on dementia and nondementia patients and their caregivers. *Psychology and Aging*, 3, 38-42.

Conlin, M.M., Caranasos, G.J., & Davidson, R.A. (1992). Reduction of caregiver stress by respite care: A pilot study. *Southern Medical Journal*, 85, 1096-1100.

Lawton, M.P., Brody, E.M., & Saperstein, A.R. (1989). A controlled study of respite service for caregivers of Alzheimer’s patients. *The Gerontologist*, 29, 8-16.

Mohide, E.A., Pringle, D.M., Streiner, D.L., Gilbert, J.R., Muir, G., et al. (1990). A randomized trial of family caregiver support in the home management of dementia. *Journal of the American Geriatrics Society*, 38, 446-454.

Pearson, N.D. (1988). An assessment of relief hospital admissions for elderly patients with dementia, *Health Trends*, 20, 120-121.

Folden, S.L., & Coffman, S. (1993). Respite care for families of children with disabilities. *Journal of Pediatric Health Care*, 7, 103-110.

This article is a descriptive survey of various research evaluations. It describes family members' needs for respite and the types of respite available to them. It also looks at benefits of respite and examines the roles that nurses can play in assisting families to access this essential service.

A 1987 study (Horner, Rawlins & Giles) surveyed 164 parents caring for a child with a chronic illness or disability. "Three of the top six service needs identified by these parents were related to child care. Child care for emergencies was a need identified by 28%, child care for recreation by 24%, and child care while working by 23% of parents." (p. 104)

Cohen and Warren (1985) found that "families using respite reported increased satisfaction with life, more hope for the future, improved attitudes toward their child with a disability, and increased ability to cope. Most user families (94%) recommended respite services to other families" (p. 106).

Marc and MacDonald (1988) reported that families experienced "better family functioning and reduced stress levels after the use of services" (p. 106).

Joyce and Singer (1983) cited four frequently identified benefits of respite care: "(a) the relief of having a trained person available to care for their child, (b) a decrease in the strain they felt as caretakers, (c) the ability to make plans ahead of time, and (d) less guilt about leaving their child" (p. 106).

"The major finding from the three studies is that parents, whether caring for a child with mental or physical disabilities, have common service needs. The most frequently expressed need is respite from care giving to promote family health." (p.103)

"Researchers have found that respite does improve family functioning, therefore documenting its essential place in the multitude of services required by these families. Unfortunately, respite services for families of children with disabilities are presently fragmented, under coordinated, and poorly financed. Because of the lack of in-home services or lack of awareness of services available, families seek out-of-home long-term respite services. These services are often sought after damage to the family unit has already occurred." (p. 109)

Folden, S.L., & Coffman, S. (1993). Respite care for families of children with disabilities. *Journal of Pediatric Health Care*, 7, 103-110. (continued)

Citations referred to in the annotations above and cited with the article's references:

Cohen, S. & Warren, R. (1985). *Respite care: Principles, programs, and policies*. Austin, TX:Pro:Ed, Inc.

Horner, M., Rawlins, P., & Giles, K. (1987). How parents of children with chronic conditions perceive their own needs. *American Journal of Maternal Child Nursing*, 1240-43.

Joyce, K., & Singer, M.I. (1983). Respite care services: An evaluation of the perceptions of parents and workers. *Rehabilitation Literature*, 44, 270-274.

Marc, D., & MacDonald, L. (1988). Respite care: Who uses it? *Mental Retardation*, 26, 93-96.

Gaugler, J. E. & Zarit, S. H. (2001). Effectiveness Of Adult Day Services For Disabled Older People. *Journal of Aging and Social Policy*, 12, (2), 23-47.

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Assessed the effectiveness of adult day services for disabled older adults. All studies of adult day care published after 1975 were reviewed by conducting an extensive search on the MEDLINE and PsychINFO databases. Research that focuses on activities of daily living dependency, behavioral disturbances, and related health variables implies that adult day centers do not affect functional outcomes consistently, if at all. However, when evaluations include outcomes that focus on subjective aspects of well-being, such as morale, mood, and satisfaction, it appears as though adult day programs exert positive effects. Adult day services can be quite effective in providing caregivers with emotional and psychological relief from the daily demands of care. However, this occurs only when families choose to utilize adult day services consistently and over time. Older Americans and their families are already delaying institutionalization, and adult day programs are unlikely to have a demonstrable effect on overall nursing home rates. However, programs such as Programs of All Inclusive Care for the Elderly and Arizona's Long-Term Care System appear effective in reducing institutionalization, particularly if adequate targeting mechanisms are in place to ensure that those who are enrolled are at risk for nursing home placement. Results suggest that programs that emphasize psychosocial benefits, as opposed to intensive rehabilitation, may prove more appropriate and feasible for clients. (AR) (Ageline Database, copyright 2001 AARP, all rights reserved)

“An initial review of the literature suggests that programs that emphasize psychosocial benefits, as opposed to intensive rehabilitation, may prove more appropriate and feasible for clients.” (p. 39)

“As a review of the literature implies, medical models of adult day services have not demonstrated more positive effects on clients when compared to social models. Therefore, federal regulations designed to offer medical-style adult day care may actually provide no tangible benefits to clients, restrict consumer choice, and increase overall costs. (p. 40)

“Adult day services may prove most effective not when they attempt to provide both medical and psychosocial services on their own, but instead work as a single component in an integrated network of long-term and acute care services designed to maintain the impaired older adult in the community (for example, PACE). As this review suggests, adult day services are best at: (1) providing respite and relief to family caregivers, and

Gaugler, J. E. & Zarit, S. H. (2001). Effectiveness Of Adult Day Services For Disabled Older People. *Journal of Aging and Social Policy*, 12, (2), 23-47.

(continued)

(2) improving psychosocial outcomes among elderly clients. Medically-oriented services designed to improve client functioning may be best administered via other community-based care services (such as home health care) offered through integrated programs.” (p. 41)

“As the results of this review suggest, adult day services appear relatively effective in relieving specific dimensions of caregiver stress and psychological well-being.” (p. 41)

“Also, providing caregivers with adult day services early in the progression of an elderly relative’s impairment may better demonstrate the effectiveness of these programs. Little research focuses on the linkages between informal and community-based care systems during various time points in the caregiving career (Lyons & Zarit, 1999).” (p. 42)

“Elderly clients are largely satisfied with adult day services and appear to enjoy improvements in psychosocial functioning. In addition, family caregivers seem to benefit from utilizing adult day services over time” (p. 44)

“These findings imply that experts should pay special attention to the program content, timing, and targeting of adult day programs in order to improve overall effectiveness. Moreover, researchers must gain a better understanding of effectiveness by utilizing larger samples, incorporating more rigorous experimental designs, and evaluating different types of programs (that is, social models) as well as multi-component approaches.” (p. 44)

Citation referred to in the annotations above and cited with the article’s references:

Lyons, K.S., & Zarit, S.H. (1999). Formal and informal support: The great divide. *International Journal of Geriatric Psychiatry*, 14, 183-196.

Gerard, K. (1989). Determining the contribution of residential respite care to the quality of life of children with severe learning difficulties. *Child: care, health, and development*, 16, 177-188.

This paper looks at factors that may influence the impact of residential respite services on the residents' quality of life. The focus of benefits is on the "patient" — not the caregiver. Residents were individuals under 19 years of age with severe learning difficulties. Caregivers who had used the residential respite services for their dependent family members were asked to respond to a questionnaire that asked about their child's quality of life.

The design of the study concentrated on a comparison of users of three residential services; it was not a random, experimental study. The three services were not well described. Outcomes focused predominantly on determining whether the quality of life of the resident improved, declined, or appeared not to change. In all three services, more than 50% of the residents were found to have an improved quality of life, according to the perception of the caregiver.

"The analysis of outcomes of respite care for residents appears to produce an overwhelming majority of good effects on residents' quality of life according to the advocates' interpretation of the situation." (p. 187)

Gottlieb, B. H., & Johnson, J. (2000). Respite Programs For Caregivers of Persons With Dementia: A Review With Practice Implications. *Aging and Mental Health*, 4, (2), 119-129.

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Reviews critically the evidence concerning the role and impact of center-based respite programs for family caregivers of persons with dementia. Conceptual and empirical articles appearing in the scholarly literature since the late 1980's are examined in addition to the finding of the authors' unpublished prospective study of 16 day programs in Ontario, Canada. For the present review, the authors examine the timing, intensity, and duration of day program utilization; expectations that caregivers bring to these programs; and the impacts derived from program participation, drawing on this information to propose ways of optimizing the role played by respite care programs. It is concluded that the timing and extent of center-based respite care use can be summarized by the phrase, "Too little, too late." When offered the service, between one-third and one-half of caregivers do not use it, and those who voluntarily enroll tend to do so between 2 and 4.5 years after beginning their caregiving work. In addition, attrition is high and occurs relatively soon after program commencement. The evidence on the impact of respite programs on caregivers reveals that any significant effects are very modest. Suggestions for making center-based respite care a more effective supportive service are explored. (KM) (*Ageline Database, copyright 2000 AARP, all rights reserved.*)

Grant, G., & McGrath, M. (1990). Need for respite-care services for caregivers of persons with mental retardation. *American Journal on Mental Retardation*, 94, 638-648.

This survey of 190 North Wales' families focused on the management of challenging behavior of persons with mental retardation. While the paper does not focus on outcomes, it does describe useful descriptions of families' needs and preferences.

Behavioral demands and the need for continuous surveillance of the child were identified as factors that could cause severe disruption to families. The areas of help families needed most were respite care and help with minding their children.

“Hardships associated with physical dependency and behavior and behavior problems were also highlighted by caregivers' responses to a question posed about how long they could leave the mentally retarded person alone. Nearly half felt that they could not do so at all or not for more than 10 minutes, and only 22% were able to leave him or her alone for several hours.” (p.641)

“There were many reasons for requesting short-term care and other reasons for requesting short-term care and other minding services, including extending the interests of the persons with mental retardation, increasing community integration, and preparing individuals for a different living situation, but respite for caregivers seemed to predominate.” (p.643)

Gravelle, A.M. (1997). Caring for a child with a progressive illness during the complex chronic phase: Parents' experience of facing adversity. *Journal of Advanced Nursing*, 25, 738-745.

This was a qualitative study that examined the experiences of Canadian parents caring at home for a child with a progressive life-threatening illness. Parents considered respite care one of the most useful resources. Respite care was crucial for parents, although existing respite care services did not meet the needs of all parents. One form of respite care does not meet all needs: "home-based respite may be desired in most instances. However, institutional-based respite is also necessary and desirable in certain circumstances" (p. 744).

Accessing services was cited as a difficult issue with many of the parents as reflected in the following comment made by a parent ". . . probably the thing I find the most stressful is trying to get services, and having to fight the system or the bureaucracy. It's so exhausting and that's what wears me out the most" (p.742).

"The issue of respite care came up with every family. Parents were at different points of requiring and utilizing respite care. One mother described her growing realization of changing respite needs. Her daughter was requiring increasingly specialized care, and she became more and more uncomfortable with the idea of lay people watching her daughter." (p.743)

Guttman, R. A. (1991). Adult Day Care for Alzheimer's Patients: Impact on Family Caregivers. *Garland studies on the elderly in America*; 9, 175. Garland Publishing, New York, NY.

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Assessed the effects of adult day care (ADC) on caregivers of patients with Alzheimer's disease (AD) in terms of stress levels, morale, feelings of burden, and ability to continue to provide care. Problematic behaviors and aspects of care that created high stress levels were determined, and the effectiveness of various coping strategies was evaluated. A model was created to predict which combinations of stress levels, patient and environmental factors, demographics, and intervention would avert institutionalization. The sample consisted of 118 female primary caregivers (mean age 59) to community-dwelling patients with AD or an associated disorder. Sixty-three caregivers received help from ADC programs, and 55 received no caregiving respite. Respondents completed a 176-item baseline questionnaire and a follow-up questionnaire 6 months later. Descriptive analyses were performed on the two groups at Baseline and at 6 months, and differences occurring within and between groups at both times were assessed. Results showed that the respite and nonrespite groups were similar on most baseline dimensions, but the respite group had a higher desire to institutionalize and the nonrespite group reported higher mean hospital admissions and longer lengths of stay. At 6 months, the respite group showed a decreased desire to institutionalize the patient, spent fewer hours in caregiving tasks, had fewer hospital admissions and shorter lengths of stay, and had less global stress than at the baseline survey. For both caregiver groups, the main predictive variables of willingness to institutionalize the patient were initial desire, use of ADC, and stress. For both groups, high levels of stress were associated with high levels of somatic complaints and low levels of psychological well-being. A literature review on the impact of caregiving on the family member is included. Items of the caregiver questionnaire are appended. (PH) (*Ageline Database, copyright 1993 American Association of Retired Persons, all rights reserved.*)

Hall, D.M.B., West, R.J., & Bungay, C.J. (1986). Respite care on a children's ward. *British Medical Journal*, 293, 191-192.

This article describes the opening of a short-term respite care facility in a children's ward of a hospital for children who are handicapped. The authors found that short term respite care was highly valued by their patients' families, and so undertook the creation of this four-bed facility, which could revert to acute care when needed.

The facility, opened in 1984, proved to be very popular with parents. Families served at other hospitals have tried to arrange transfer to this hospital in order to qualify for the service. While the authors believe that short term, NON-hospital respite is better and less expensive, they maintain that their service helps patients and families and "also provided a useful learning opportunity for medical students and junior staff" (p. 192).

"The already heavy burden on the parents caring for these children is increased when accommodation or income is inadequate, when the parents are separated, or there is no support from the extended family. All of these problems are common, especially in the inner-city area. In addition, a severely handicapped child in the family causes considerable stresses on the parents' marriage and health and on the normal siblings." (p. 191)

Halpern, P.L. (1985). Respite care and family functioning in families with retarded children. *Health and Social Work*, 10, (2), 138-150.

Families using respite care were compared to nonusers, in ten specific areas of family functioning, using Moos's Family Environment Scale (FES). The study indicates that the use of respite care makes a difference in the ability of families to recover from stress, by maintaining and strengthening family functioning in selected areas. The study found evidence to support the premise that in some areas, respite care is useful in maintaining family stability.

“An example of this was provided by one couple in the study's sample, who used respite to help their disabled child arise and get on the bus in the morning, while the wife was recuperating from an operation. If the family had not been able to use respite, the child's schooling or the husband's employment would have been disrupted.” (p. 144)

“The greater the amount of respite care a family used, the lower the mother's score on the Conflict scale, the higher both parents' scores on the Organization subscale...in other words, the less conflict family members perceived and the more they saw their family as having organization...” (p. 143)

“One mother indicated that, for her, respite care took the place of therapy.” (p. 147)

“Although further research is called for, this study indicates that the use of home-based respite care makes a difference in the ability of families with retarded children to recover from stress by maintaining and strengthening family functioning in selected areas.” (p.149)

Citation referred to in the annotations above and cited with the article's references:

Moos, Insel, & Humphrey, (no date given). Family Work and Group Environment Scale Manual: *Career/LifeSkills Resources Inc.*: Ontario, Canada

Home, A., & Darveau-Fournier, L. (1995). Respite child care: A support and empowerment strategy for families in a high-risk community. *Prevention in Mental Health and Human Services, 12, (1), 69-88l.*

This paper describes a respite-care project designed to prevent the deterioration of the family and to foster family empowerment. The families studied lived in a high-risk community and were characterized as “under stress.”

Twenty-four hour a day respite care was offered, for 2 to 15 days. The families could use the service “several times a year.” Local families who were accredited “on the basis of their motivation, their parenting ability, their health, and the quality of the physical setting” provided the respite services.

“Sixty percent of the 52 respondents who were interviewed identified physiological and psychological rest as the principal effect of respite care.” (p.80)

“One quarter of the women reported some positive change in their relationship with their children, such as better communication.” (p.80)

“Half of the 52 mothers noted positive changes in their children’s behavior, such as greater independence, improved eating habits, or improved language skills.” (p.80)

“The provision of local care by community families reduced the adaptation required of the children, thereby minimizing disruption to their lives and possibly preventing some behavior or academic problems.” (p. 83)

“Periodic availability of care prevented stress accumulation which might have led to some mothers’ hospitalization and to the neglect and eventual placement of the children.” (p.83)

“The limited data regarding prevention of placements suggests the respite care service may have enabled some families to avoid placing their children in foster homes outside the community. Of the 25 families referred to the project following a request for placement, over two-thirds did not proceed with placement plans.” (p. 81)

Homer, A.C. & Gilleard, C.J. (1994). The Effect of Inpatient Respite Care on Elderly Patients and Their Carers. *Age and Aging*, 23, (4), 274-276.

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Examined caregivers' impact assessment of a respite care program for geriatric inpatients in England. A sample of 54 caregivers for 58 paired inpatients receiving respite care while hospitalized were interviewed pre- and posttreatment in the caregiver's home. Caregivers aged 37-91 (mean age 66) completed a version of the General Health Questionnaire (GHQ-28) to assess their emotional health and the CAPE Behaviour Rating Scale (BRS) as a measure of their dependent's functional ability. Nurses on the patients' wards were asked to complete the BRS assessment of patient functioning. Although there was no observable improvement in the caregivers' emotional well-being, the majority of the patients showed an improvement in functioning, particularly those being looked after by highly stressed caregivers. Caregivers believed the respite services to be worthwhile, expressed a wish for more respite care, and expressed a need for alternative respite services—usually in the form of day care services. (TS) (Ageline Database, copyright 1994 AARP, all rights reserved)

“...while carers generally do not show any marked improvement in well-being during the course of their dependants' inpatient respite admission stay, the patients themselves more often than not show signs of improved functioning. Although patients were not routinely seen by therapists during their stay, nursing care was individualized on the respite care wards, and this style of nursing has been shown to foster greater physical independence [9]. We found that the greatest improvement in functioning was associated with patients looked after by highly stressed relatives, particularly patients who were not suffering from dementia.” (p. 275-276)

“Many of the problems of caring for elderly dependants are not addressed by removing the patient from the home for a break, which may not be what the carer wants [11], and more flexible ways of responding to carers' needs for relief seem to be called for if true respite is to be provided for them [12].” (p. 276)

Citation referred to in the annotations above and cited with the article's references:

Melzer D. An evaluation of a respite care unit for elderly people with dementia: framework and some results. *Health Trends* 1990;22:64-7.

Griffin D. Respite care. *Br Med J* 1993;**306**:160.

Houde, S. C. (2001). Men Providing Care To Older Adults In The Home. *Journal of Gerontological Nursing*, 27, (8), 13-19.

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Provides an overview of research related to the role of the male caregiver and discusses implications for supportive interventions. Data on 516 male caregivers who participated in the 1982-1984 Channeling Study suggested that men provided less direct care related to activities of daily living than women (Chang and White-Means, 1991). Many studies have addressed social support and the family caregiver, but few have examined gender difference in social support and implications for nursing interventions. Research has suggested that men generally have different responses to caregiving than women. However, research has shown that men do experience a feeling of social isolation (Harris, 1995), and it has been suggested that respite care may be an important service for male caregivers (Harris, 1995; Kaye, 1997; Kramer, 1997). Adult day care may be a helpful service for male caregivers to assist them in addressing the issue of social isolation. A challenge for the gerontological nurse is to develop programs that help sustain men in the role of caregiving by providing support and education. (AR) (*Ageline Database, copyright 2001 AARP, all rights reserved.*)

Citations to the articles referenced in the above abstract were unavailable to ARCH at press.

Intagliata, J. (1986). Assessing the impact of respite care services: A review of outcome evaluation studies. In C.L. Salisbury and J. Intagliata's *Respite Care: Support For Persons With Developmental Disabilities and Their Families*. Baltimore: Paul H. Brooks Publishing

This chapter describes some of the shortfalls of research associated with outcomes of respite programs. Many published studies (many described in this document) suggest respite care produces various favorable outcomes such as decrease in stress levels, diminishing dysfunctional family patterns, less social isolation, more positive parental attitudes toward children, less likelihood of institutional placement, and improvement of the behavior of the person with disabilities. This chapter further presents some convincing arguments that there are reasons to question these findings. The author cautions that the studies were weak in methodology and thus produced weak outcomes. This chapter would be valuable reading for anyone planning to evaluate a respite program.

Of the various outcomes the author examines, the most dramatic, he claims, is that of reduced out-of-home placements. He finds little evidence for this, citing four studies. One (Pagel & Whitling, 1978) reported that the most frequently given reason for readmission of patients to an institution was lack of respite care. In another (Joyce et al, 1983), 30% of families said they could not “care for their son or daughter at home without respite care” (p. 282). The California Institute on Human Services (1982) reported 47% of 98 families “would have to consider out-of-home placement if respite were unavailable” (p. 282).

Finally, Cohen (1980) reported that 29% of 107 respite users “felt that they ‘would not have been able to cope’ without respite. However, when the user group was compared with a control group of 35 nonuser families, a significantly higher proportion of user families indicated that out-of-home placement was likely” (p. 283).

Citations referred to in the annotations above and cited with the article's references:

California Institute on Human Services. (1982). *Respite services for Californians with special developmental needs*. Sacramento: California State Council on Developmental Disabilities.

Cohen, S. (1980) *Final report: Demonstrating model continua of respite care and parent training services for families of persons with developmental disabilities*. New York: City University of New York, Graduate School, Center for Advanced Study in Education, Education Development Center.

Intagliata, J. (1986). Assessing the impact of respite care services: A review of outcome evaluation studies. In C.L. Salisbury and J. Intagliata's *Respite Care: Support For Persons With Developmental Disabilities and Their Families*. Baltimore: Paul H. Brooks Publishing (continued)

Joyce, K., Singer, M., & Isralowitz, R. (1983). Impact of respite care on parents' perception of quality of life. *Mental Retardation*. 21, 153-156.

Pagal, S. E., & Whitling, B. (1978). Readmissions to a state hospital for mentally retarded persons: Reasons for community placement and failure. *Mental Retardation*. 16(2), 164-166.

Jarrott, S. E., Zarit, S. H., Berg, S. & Johansson, L. (1998). Adult day care for dementia: A comparison of programs in Sweden and the United States. *Journal of Cross-Cultural Gerontology*, 13, 2, 99-108.

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Compared adult day programs for dementia patients in Sweden and the United States. A survey of 178 Swedish and 86 American day care centers serving cognitively impaired clients was conducted to assess staff and organizational characteristics. Results revealed that day care programs in both countries served similar groups of approximately the same age and for the same length of time. Notable differences between the countries reflect quality of care issues. Unlike the United States, Sweden does not have formal admission policies and offers greater access to geropsychiatric services. Staff in Sweden have less formal training and offer clients lower rates of formal activities. Almost all the American centers offered services to family caregivers compared to almost none at the Swedish centers. Results suggest that day care centers can be both a humane and cost-effective way of addressing disabilities in later life while relieving dementia patients' families of a portion on the burden of care. (AG) (*Ageline Database, copyright 1999 AARP, all rights reserved.*)

“Besides the overall similarities, there were several notable differences between Sweden and the USA.” (p. 105)

“The first difference concerned policies about admission criteria. The American programs were much more likely to have specific rules about the types of clients they would not admit into the program, such as people who were agitated or incontinent. The absence of formal admissions policies in Sweden may reflect the belief that day care should be available to all who need it.” (p. 105)

“The second main difference is that the staff of day care programs in Sweden had lower formal training than in the USA. Whereas staff in the USA had varied professional qualifications, which included nurses, social workers and recreational therapists, the typical staff in Sweden were nurses' assistants or recreational aides.

Reflecting these differences in staff, the programs in Sweden also had lower rates of formal activities. The American day care centers offered a varied program of structured activities. We do not know how much the actual daily activities vary between the USA and Sweden, but there is a clear difference in preferring a more formal approach in the USA.” (p. 106)

Jarrott, S. E., Zarit, S. H., Berg, S. & Johansson, L. (1998). Adult day care for dementia: A comparison of programs in Sweden and the United States. *Journal of Cross-Cultural Gerontology*, 13, 2, 99-108. (continued)

“One of the most striking differences was in terms of offering services for family caregivers. These types of services were offered by almost all American day care centers and almost no Swedish day care programs.” (p. 106)

“We have seen in both Sweden and the USA that people with dementia remain in day care centers for approximately two years, and then typically go into an institution such as a nursing home or group home. It is reasonable to assume that if day care centers were not available, clients would spend at least part of that two year period in an institutional setting. From this perspective, day care centers are a cost-effective way of providing help to dementia patients and their families.” (p. 106)

Jarrott, S. E., Zarit, S. H., Parris-Stephens, M. A. Townsend, A., & Greene, R. (1999). Caregiver satisfaction with Adult Day Service Programs. *American Journal of Alzheimer's Disease*, 14, (4), 233-244.

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Evaluated caregiver satisfaction with adult day service (ADS) programs designed for older adults with dementia. A total of 261 primary caregivers (mean age 59.2) of older adults with dementia (mean age 78.5) completed an initial interview at the time of enrollment in one of 45 ADS programs. The interview focused on demographic variables, program satisfaction, and the benefits and drawbacks of the program. Follow-up interviews were conducted with 175 caregivers after 3 months of program use and with 90 caregivers after 12 months of program use. It was found that caregivers with lower baseline levels of depression or greater baseline overload levels reported more benefit to the care recipients. Caregivers with lower baseline levels of overload, those whose relative had more behavior problems, and non-employed caregivers reported more benefits for themselves from sending their relative to ADS programs. Female caregivers and caregivers with lower baseline levels of worry reported a greater frequency of problems due to the use of ADS programs. (MM) (Ageline Database, copyright 1999 AARP, all rights reserved)

“Examination of mean scores shows that caregivers in this study were highly satisfied with all aspects of the program their relative was attending.” (p. 238)

“Caregiver depression and overload were significantly associated with benefits to the care-recipient. Caregivers with lower baseline levels of depression or greater base-line overload levels reported more benefits to their relative as a result of ADS use.” (p. 238)

“Caregivers with lower baseline levels of overload, those whose relative had more behavior problems and non-employed caregivers reported more benefits for themselves from sending their relative to ADS programs.” (p. 238)

“The second part of our analyses addressed change in satisfaction with and benefits and drawbacks from ADS over a year.” (p. 238)

“Caregivers report that ADS benefits themselves and their relatives with dementia. Reports of benefits and drawbacks were more useful for differentiating among caregivers than were questions about satisfaction.” (p. 240)

“Those with lower levels of depression and higher levels of overload at the initial interview are more likely to report benefits for their relatives, including reduced agitation, following ADS attendance.” (p. 240)

Jarrott, S. E., Zarit, S. H., Parris-Stephens, M. A. Townsend, A., & Greene, R. (1999). Caregiver satisfaction with Adult Day Service Programs. *American Journal of Alzheimer's Disease*, 14, (4), 233-244. (continued)

“Paradoxically, while depressed caregivers may need the type of help provided by ADS, they may be less likely to view it as helping their relative. A multifaceted approach may be needed, which combines respite with services that directly address caregivers’ depression. By contrast, caregivers with higher overload, which is specifically related to caregiving routines, are more likely to view ADS as helping their relative.” (p. 243)

Joyce, K., Singer, M., & Isralowitz, R. (1983). Impact of respite care on parents' perception of quality of life. *Mental Retardation*, 21, (4), 153-156.

In this study, 32 families of children with disabilities who used respite care over a four-month period were questioned about the impact of services on a variety of areas. A positive impact on their family relations, social activities, emotional and physical strains, and plans for institutional care was demonstrated. The families with younger children were more likely to consider the services helpful than those families with older children or adults needing care.

“Overall, parents’ perceptions of respite care services indicated such services had a positive impact upon the lives of participant families. Respite care, according to parents’ responses, had a positive effect on family relations.” (p.154)

“Fifty-three percent of the parents either strongly agreed or agreed that they had been relating better to their disabled son or daughter since receiving respite care services.” (p.154)

“Approximately 53% either strongly agreed or agreed that their family gets along better since receiving respite care services.” (p.154)

“When asked whether respite care had helped to relieve family stress, 68% agreed or strongly agreed and 16% disagreed or strongly disagreed.” (p.154)

“Ninety-six percent said respite care has allowed them to make social plans ahead of time.” (p.154)

“Seventy-six percent either agreed or strongly agreed they can now do things that were not possible prior to respite care services (such as travel out of the city or stay away from home for longer periods of time).” (p.154)

“Seventy-seven percent said respite care had allowed them to feel less guilty when they left their son or daughter.” (p.154)

“Most respondents, 55% either strongly disagreed or disagreed that they had at times considered institutionalizing their son/daughter. However, 91% agreed or strongly agreed that respite care programs can help parents avoid institutionalizing their disabled son or daughter.” (p.154)

Kissman, K. (1999). Respite from stress and other service needs of homeless families. *Community Mental Health Journal*, 35, 241- 249.

This paper describes the results of a qualitative study of 42 homeless mothers who were who participated in an outdoor camping program with their children. The camp was designed as “time out from the stressful conditions of shelter living.” (p.241) The camp experience was also intended to strengthen parental skills and family communication among participants. Most families were very satisfied with camp and welcomed the opportunity for the children to participate in outdoor activities.

“The program was reported to help families engage in more activities together and to be more in tune with the need to keep children occupied to prevent acting out behavior in the close confines of the shelters. Interventions and modeling of positive adult/child interactions by caring counselors and the supportive atmosphere at camp enhanced playful interactions between parents and children.” (p. 247)

“Although families found the short respite from stress and parental skills discussion groups helpful, the most gratifying experiences for many families included informal activities such as gazing at the stars and singing in front of the camp fire.” (p. 247)

Kosloski, K. & Montgomery, R.J.V. (1993). Perceptions of Respite Services as Predictors of Utilization. *Research on Aging*, 15, (4), 399-413.

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Investigated the factors that influence the extent to which family caregivers of Alzheimer's patients use publicly subsidized respite programs. Data were collected on 114 caregivers in Michigan, using structured interviews in the home. Caregivers averaged slightly over 62 years of age, 72 percent were female, and 58 percent were the spouse of the Alzheimer's patient. Care receivers had an average age of 77, and 59 percent were female. The primary dependent variable was the extent to which the caregiver used the Model Respite Program sponsored by the state of Michigan. Caregivers were asked to estimate the number of times they had used the respite program in the last 6 months; a second estimate was obtained from agency personnel and available records. Three broad categories of control variables were also included: need of the care receiver, need of the caregiver, and the use of other support service. The findings support the view that beliefs held by caregivers about relevant aspects of respite programs affect their use of those programs. In particular, beliefs about the quality of care associated with a particular service and the overall usefulness of that service exerted substantial influence on the level of respite use. The perceived convenience of the respite service was also important, but primarily to the extent that it influenced caregivers' perceptions of overall usefulness. (SW) (*Ageline Database, copyright 1993 AARP, all rights reserved.*)

“A potentially productive avenue in explaining the use of support services, then, would appear to involve a closer examination of the perceptions, attitudes, and beliefs about supportive services held by the potential users of those services. Extending this line of reasoning, the purpose of the present study was to determine whether attitudes held by caregivers concerning respite services influenced their use of those services.” (p. 401)

“Both perceived utility and quality of care had substantial, significant direct effects on the extent of respite use, controlling for need of the elder, need of the caregiver, and the use of other services.” (p. 408)

“The present findings support the view that beliefs held by caregivers about relevant aspects of respite programs affect their use of those programs. In particular, beliefs about the quality of care associated with a particular service, and the overall usefulness of that service in their particular caregiving situation, exerted substantial influence on the level of respite use. The perceived convenience of the respite service was also impor

Kosloski, K. & Montgomery, R.J.V. (1993). Perceptions of Respite Services as Predictors of Utilization. *Research on Aging*, 15, (4), 399-413. (continued)

tant, but primarily to the extent that it influenced caregivers' perceptions of overall usefulness." (p. 409)

"Given these caveats, perhaps the most significant outcome of the present study was the substantial proportion of variance explained by the attitudinal variables. A number of factors likely contributed to this outcome. First, the initial model appears to have been reasonably well specified. That is, with respect to respite care, issues of quality, convenience, and overall usefulness are clearly relevant. Second, it was clearly beneficial to relate these attitudinal dimensions to the use of specific service programs.

"...several of the findings appear to have direct implications for targeting potential users of respite programs. For example, the negative relationship observed between ADL and respite use suggests that respite care is of greatest relevance to caregivers whose elder is not extremely impaired." (p. 410)

"...the results suggest that a focus on consumer-related issues may increase utilization rates of respite programs. Specifically, any programmatic changes that favorably affect caregivers' perceptions of program quality, convenience, and overall usefulness are likely to increase utilization." (p. 411)

Kosloski, K. & Montgomery, R. J.V. (1995). The Impact of Respite Use on Nursing Home Placement. *Gerontologist*, 35, (1), 67-74.

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Investigated the relationship of respite care to nursing home placement for elderly patients. The results of a previous study are reanalyzed, based on the behavioral model of service use that identifies needs, enabling, and predisposing factors as the primary determinants of service use. Data were derived from a study of the effects of family support programs, based on a subsample of 181 dyads composed of an elder who had at least two limitations in activities of daily living (ADLs) and a family member serving as a caregiver. Data were collected in two waves 12 months apart. At Time 1, all elders resided in the community; at Time 2, 126 patients were still living and available for analysis, of whom 30 (24 percent) had been institutionalized. In the present study, the characteristics of the sample were reanalyzed with amount of respite care used as the primary independent variable. Family members were able to choose any of four types of respite: a short nursing home stay, adult day care, home health aide, or a visiting nurse. Each family was eligible for up to \$882 of free respite services that were offered through a Medicare waiver. Other variables included elder's need, caregiver's need, enabling factors (elder's income), and predisposing factors (closeness of caregiver to elder, and age of elder). Logistic regression was used to evaluate the effects of the amount of respite use and the other covariates on nursing home placement. Ordinary least squares regression was used to estimate the effects of the amount of respite use and the other covariates on the length of time spent in the nursing home during the one-year study period. Results showed that as respite care use increased, the probability of nursing home placement decreased significantly. The impact of respite use persisted, even after controlling for the effects of 11 other variables, including age and level of disability, the presence of Alzheimer's disease, and the use of other supportive services. (TS) (*Ageline Database, copyright 1995 AARP, all rights reserved.*)

“The results of this reanalysis would appear to provide evidence to support the utility of respite as a potential intervention to delay or decrease the likelihood of nursing home placement. Specifically, as respite use increased, the probability of nursing home placement decreased significantly.” (p. 73)

Kosloski, K. & Montgomery, R. J.V. (2001). Utilization of Respite Services: A Comparison of Users, Seekers, and Nonseekers. *Journal of Applied Gerontology*, 20, (1), 111-132.

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Examined the use of respite services by caregivers of older adults with Alzheimer's disease (AD). A total of 458 family caregivers of AD patients in Michigan were interviewed to identify factors associated with respite use. Of these caregivers, 176 (mean age 63.1) were using respite services, 128 (mean age 62.3) had inquired about the service but had not yet used it, and 154 (mean age 62.2) had neither used nor inquired about respite. Participants completed measures of need for assistance, beliefs about personal responsibility, aspects of service delivery, and demographic characteristics. Separate logistic regression models were evaluated to identify users versus nonusers and seekers versus nonseekers. Need for assistance with activities of daily living, availability of caregivers, concern with cost, and adherence by the respite program to an established service schedule contributed significantly to the model distinguishing service users from nonusers. Caregiver burden, the presence of other caregivers, and the availability of transportation services made significant, unique contributions to the model distinguishing seekers from nonseekers. Seekers exhibited the highest caregiving burden, followed by users and then nonseekers. (MM) (*Ageline Database, copyright 2001, AARP, all rights reserved.*)

Larkin, J. P. & Hopcroft, B. M. (1993). In-Hospital Respite as a Moderator of Caregiver Stress. *Health and Social Work, 18, (2), 132-138.*

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Data on family caregiver stress obtained before, during, and following respite suggest that stress was moderated by an in-hospital respite program for patients with Alzheimer's disease. Although short-term benefits may be realized for caregivers, in-hospital Alzheimer's respite care may present a particular risk for patient decline, adverse events, and institutionalization.

“Improvement in caregiver sleep behavior was considered a major benefit from the respite experience.” (p. 134)

“...the symptomatology of anxiety, hostility, and depression that has been linked to long-term caregiving (O'Quinn & McGraw, 1985) were significantly reduced during the respite period.” (p. 136)

“The authors' clinical impression is that for many caregivers, in-hospital respite was used as a last resort. As such, caregivers viewed their support network and personal resources as nearly depleted; patient needs were seen as increasing. Thus, the physical and emotional relief obtained by respite, when combined with a positive perception of institutional care, made the resumption of caregiving at home a less attractive alternative.” (p. 137)

“If the primary goal of respite is to provide families with a temporary relief from the stress of continuous caregiving, this institutional respite program may be effective in realizing this objective. Respite may also function as a prelude to long-term institutional placement of the Alzheimer's patient.” (p. 137-138)

Citation referred to in the annotations above and cited with the article's references:

O'Quinn, J.A., & McGraw, K.O. (1985). The burdened caregiver: An overview. In J.T. Hutton & A.D. Kennedy (Eds.), *Senile dementia of the Alzheimer type* (pp. 65-75). New York: Liss.

Lawton, M. P. Brody, E. & Saperstein, A. (1989). Respite Care For Alzheimer's Families: Research Findings and Their Relevance to Providers. *American Journal of Alzheimer's Care and Related Disorders and Research*, 4, (6), 31-38.

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Evaluated effects of a year-long respite care program for caregivers of patients with Alzheimer's disease and related conditions. The Philadelphia Geriatric Center provided an experimental respite service to 315 volunteer families. Of these, 60 percent used in-home respite, 39 percent used day care, and 15 percent used nursing home respite. However, some of these services were not provided by the experimental project. Although the offer of experimental respite care did slow the caregiver's readiness to seek permanent institutional placement, the delay was only 22 days. The experimental group reported significantly greater relief and greater satisfaction than a control group. The emotionally supportive function was very highly valued by caregivers, as was the ability of the project to help them put together an entire service package that included respite plus other in-home services. It is suggested that to increase the appeal of respite care to consumers, respite care must address both relief of burden and reinforcement of sources of the caregiver's satisfaction. (WD)
(Ageline Database, copyright 1990 AARP, all rights reserved.)

Leitsch, S. A., Zarit, S. H., Townsend, A. & Greene, R. (2001). Medical and Social Adult Day Service Programs. *Research on Aging*, 23, (4), 473-498.

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Evaluated the differences between medical and social adult day service (ADS) models on the program, client, and caregiver levels. The participants were 260 older adults with dementia (mean age 78.2) and their family caregivers (mean age 61.2), representing 36 ADS programs in New Jersey. A total of 106 pairs of older adults and caregivers were in a medical-model ADS program, and 154 pairs were in a social-model program. Information on ADS program characteristics was collected from 1 staff member in each ADS program, usually the program director. In addition, family caregivers rated the general atmosphere of the program, the quality of the staff-client interaction, the extent of institutional elements within the center, and the degree to which the program is home-like and familiar. Information on care recipient and caregiver characteristics, dementia severity, and the psychosocial ramifications of caring was provided by the primary caregiver at baseline and 3-month interviews. The few model differences found in program characteristics were primarily in the area of services offered, with medical programs offering more physician care, personal care, and planning services. Family caregivers rated social programs as being more home-like, having fewer institutional elements, and having increased quality of interaction between staff and clients. Throughout a 3-month period, there were no significant differences in levels of caregivers' stress or well-being or care recipients' impairment between the models. Caregivers using medical ADS models experienced greater financial strain over the cost of ADS. This study failed to confirm claims of differential advantages by proponents of each model and instead found evidence to suggest that the demands of caring for someone with dementia results in a convergence of approaches on the dimensions investigated. (AS) (*Ageline Database, copyright 2001 AARP, all rights reserved.*)

“Generally very few differences were found between medical and social ADS programs. Despite minor differences in service provision, caregiver or care recipient outcomes were not significantly different between the models. The comparison of the models is presented in six sections: (1) the program level; (2) characteristics of the care recipients; (3) care recipient ADS utilization patterns; (4) characteristics of the primary caregivers; (5) changes in dementia severity, stress, and well-being; and (6) caregivers' satisfaction with ADS.” (p. 484)

Leitsch, S. A., Zarit, S. H., Townsend, A. & Greene, R. (2001). Medical and Social Adult Day Service Programs. *Research on Aging*, 23, (4), 473-498. (continued)

“Both models were associated with decreasing the negative consequences of caregiving, irrespective of the model of the program. In accordance with the main findings of the study (Zarit et al. 1998), depression, anger, role overload, and worry all decreased over the three-month period. However, caregivers did not improve over time differentially dependent on which ADS model the care recipient attended.

One primary reason for lack of longitudinal differences in caregiver outcomes may be the similarities in important program characteristics between the models. Similar programs will result in similar outcomes, and the program and staff characteristics of ADS centers were surprisingly similar.” (p. 493)

“Finally, similarities in program characteristics suggest a convergence of the programs in meeting the needs of the population they serve. Although the philosophy of care that perpetrated the categorization of the ADS programs into either medical or social programs may have caused program differences originally, over time these programs have adapted many of their characteristics to reach the same goal: to care for similar clientele with very specific needs.” (p. 494-495)

Citation referred to in the annotations above and cited with the article’s references:

Zarit, S.H., Stephens, M.A.P, Townsend, A. & Greene R. (1998) “Stress Reduction for Family Caregivers: Effects of Adult Day Care Use.” *The Journals of Gerontology: Social Sciences* 53B:S267-77.

MacDonald, G. (1998). *Massage as a respite intervention for primary caregivers. The American Journal of Hospice and Palliative Care. 15, (1), 43- 47.*

This article describes a hospice care program that provided caregivers with massage as a component of respite. Caregivers reported that the massages were helpful in addressing many of the stresses they experienced in caring for their elderly relatives. Areas of stress included isolation, lack of time for self, and the need to be more socially active. The paper cites a study at Ohio State University (Kiecolt-Glaser, J.K., Marucha, P.T., & Malarkey, W.B., 1995) that found that “stressed caregivers took 24% longer to heal” (p. 43). Participants indicated improvement in four areas:

- Emotional stress—85% reported improvement;
- Physical stress—85% reported improvement;
- Physical pain—77% reported improvement; and
- Sleep difficulties—54% reported improvement.

“Nearly all of those who participated in an outreach project that used massage as a respite intervention reported reduced physical and emotional stress, physical pain, and fewer sleep difficulties.” (p.43)

“Caregiver fatigue is one of the primary deterrents to successful hospice intervention and is a major reason for institutionalizing patients who are in the final phases of a terminal illness.” (p. 43)

“Evidence exists that stress, depression, and grief can suppress components of the immune system, thereby increasing susceptibility to illness.” (p. 43)

“Directly caring for the primary caregiver is not only beneficial for the caregiver, but for the patient, the providing agency, and in the long run, for society through reduced health care costs.” (p. 43)

Typical responses of participants included the following:

“The massages have been extraordinarily helpful. They were very successful in relieving built-up stress.” (p. 44)

“I am more relaxed. I still have much tension, but it seems easier to handle at times. I find I don’t have to do everything right now . . .” (p. 44)

“My massages have been wonderful. I was in extreme stress both physically and emotional. I feel these massages helped me back to being a fairly normal person again.” (p. 46)

MacDonald, G. (1998). Massage as a respite intervention for primary caregivers. *The American Journal of Hospice and Palliative Care*. 15, (1), 43- 47. (continued)

“Those having just three massages showed a similar decrease in stress by the end of their participation as did those participants receiving more than three massages” (p. 46).

Citation referred to in the annotations above and cited with the article’s references:

Kiecolt-Glaser, J.K., Marucha, P.T., & Malarkey, W.B., (1995). Slowing of wound healing by psychological stress, *Lancet*, 346, 1194-1196).

Malonebeach, E.E., Royer, M. & Jenkins, C. C. (1999). Is Cognitive Impairment A Guide to Use of Video Respite? Lessons from A Special Care Unit. *Journal of Gerontological Nursing*, 25, (5), 17-21.

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Examined the usefulness of Video Respite (VR), a series of videotapes designed to provide respite for formal and informal caregivers by engaging cognitively impaired older adults in an interesting activity. The videotapes tap long-term memories, stimulate conversations, and invite participation. Three videotapes (“Favorite Things,” “Gonna Do A Little Music,” and “Remembering When”) were shown to 15 special care unit residents aged 59-94 (mean age 82.8), of whom 12 were women. Residents were videotaped as they viewed the VR videotapes to observe their levels of involvement. Impairment levels were determined using four subscales of the Multidimensional Observation Scale for Elderly Subjects (MOSES): depression or anxiety, irritability, withdrawn behavior, and disorientation. Responses to videotape-invited participation were coded on a 6-point rating scale from zero (view of participant is blocked or participant has left the viewing area) to 5 (verbal response such as answering questions or singing along). Two-tailed Pearson correlations were used to examine the relationship of each of the four subscales of the MOSES with participation score, number of days, and minutes of attendance for each of the three videotapes and for all three videotapes combined. Findings show that participation varies considerably between and within residents and, further, that cognitive status is not a useful guide in predicting levels of participation. Some residents showed no interest in television in general or in VR, while the elimination of distractions resulted in more sustained viewing for those inclined to participate. It is concluded that VR is an effective way to engage people with a wide range of impairments. (SW) (*Ageline Database, copyright AARP, all rights reserved.*)

Marks, R. (1987-1988). Stress In Families Providing Care to Frail Elderly Relatives and the Effects of Receiving In-Home Respite Services. *Home Health Care Services Quarterly*, 8, (4), 103-130.

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Evaluated the effects of in-home respite services on the stress and strain experienced by family members caring for frail elderly relatives. The primary caregiver and elderly client in 25 families who had been receiving respite care for at least one year and in 25 waiting list control families were interviewed in person. Caregivers ranged in age from 26 to 84 (mean age 60.34), and their elderly relatives ranged from 62 to 98 years of age (mean age 79.04). All of the caregivers interviewed experienced considerable stress and strain. Based on responses to the Perceived Stress Scale, the caregivers receiving respite services experienced significantly less stress than did those who were not receiving respite services. Other variables significantly related to caregiver stress were the amount of care required, the overall effect on amount of household work, and the caregiver's health. It is concluded that a formal respite service is effective in reducing the stress associated with providing full-time care to an elderly relative. (LS) (*Ageline Database, copyright 1989 AARP, all rights reserved.*)

Mausner, S. (1995). Families helping families: An innovative approach to the provision of respite care for families of children with complex medical needs. *Social Work in Pediatrics*, 95-106.

This paper describes the development, implementation and some outcomes of *Families Helping Families*, a Massachusetts social services program designed to provide cost-effective, family centered respite care for children with complex medical needs. The article includes detailed case studies that illustrate how the program addressed challenges common to many respite programs. Challenges mentioned in the article include overcoming emotional barriers to accepting respite, creating flexible schedules to meet family needs, and finding appropriate providers.

“Families Helping Families program works on the assumption that a child who is cared for at home by parents who are probably not health care professionals can also be cared for by an appropriately selected and trained ‘sharing’ family.” (p. 99)

“This program was found to be less expensive per respite stay than either traditional in-home respite or placement in a respite facility. It should be noted, however, that the program did not include the backup coverage that traditional agencies provide. If this factor is accounted for, the direct costs of the respite might be comparable. If a broader perspective is taken, however, including the total costs to society of the care of these children, significant savings could result.” (p. 103)

“Interventions of this program significantly decreased the incidence of hospitalizations, physician contacts, and need for antibiotics. The number of hospitalizations decreased by 75%, as did calls to the physician’s office. Physician visits decreased by 64%. There was a 71% decrease in the use of antibiotics.” (p. 103)

McConkey R. & Adams, L. (2000). Matching Short Break Services for Children with Learning Disabilities to Family Needs and Preferences. *Child: Care, Health and Development*, 26, (5), 429-443.

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Short breaks or respite care is a much-valued service by families and the demand for it is likely to exceed supply. It is all the more imperative that the services provided are matched to the needs and preferences of families. A census was undertaken within one Health and Social Services Board in Northern Ireland of families who received short break services for their child with disabilities during a 12-month period. Information was also collected on pertinent child and family characteristics. This enabled profiles to be drawn up of the recipients of six types of short-term breaks: (1) hospital-based overnight care; (2) overnight stays in a residential home; (3) domiciliary service in the family home; (4) breaks provided in another family home; (5) residential holidays; and (6) breaks provided through leisure schemes organized after-school or during holidays. A second study entailed interviews with families who were resident in one area served by a Health and Social Service Trust regarding their usage and preferences for each type of service noted above. This too identified variations in parental preferences and usage. This information gathered should assist commissioners in developing cost-beneficial short break services although further research is needed to validate the possible predictors for each service.

“First, there are not enough short break services to meet the demand. Nine out of 10 of the parents interviewed wished to avail of these services whereas in the Board area as a whole only one in three were able to do so in the year studied...Moreover, social workers in this study estimated that 70% of the families presently getting a service could do with more breaks.” (p. 440)

“Second, breaks in what are perceived to be hospital settings are not a favoured option. Social workers saw these as benefiting the carers rather than the child and only nominated one child as needing more of this type of break.” (p. 440)

“Third, the preference is for services that benefit the child as well as giving the carers a break. Families were near unanimous in their desire for more leisure activities and holiday breaks; a recurrent theme in the literature (McGill 1996).” (p. 440-441)

McConkey R. & Adams, L. (2000). Matching Short Break Services for Children with Learning Disabilities to Family Needs and Preferences. *Child: Care, Health and Development*, 26, (5), 429-443. (continued)

“Four, family income appears to influence the type of breaks they receive. Family-based breaks are used by more affluent families (as are leisure activities) whereas those on low incomes or benefits are more likely to use hospital or ‘institutional’ services” (p. 441)

Citation referred to in the annotations above and cited with the article’s references:

McGill, P. (1996) Summer holiday respite provision for families of children and young people with learning disabilities. *Child: Care, Health & Development*, 22, 203-212.

McGill, P. (1996). Summer holiday respite provision for the families of children and young people with learning disabilities. *Child: care, health, and development*, 22, 203-212.

This article describes a summer “play-scheme” program for children with learning disabilities. The project was piloted in the UK to examine alternatives to residential or family-based respite care programs. The authors note that little research has been conducted that focuses on the degree that respite affects the children or the adults receiving care. The play scheme, as a form of respite, was designed to be appropriately stimulating for the children and included a variety of indoor and outdoor activities as well as trips to “the zoo, parks, dockyard, and so on” (p.206). Mothers found the scheme very useful and expressed needs for more provision during the summer and other times. Children attended from 9 a.m. to 5 p.m.; transportation was provided, and the day care style set up was held in a large, ordinary house. The study confirmed that families want more respite of all kinds, reflecting families’ diverse circumstances and needs.

Semi-structured interviews were conducted with the children’s mothers as part of the evaluation process.

“Reaction to the summer day care was almost universally positive, the only common criticism being that there wasn’t enough of it.” (p. 207)

“Seventeen of the 18 mothers reported that the scheme was a success from their and their families’ point of view. All 17 felt that they had had a break and 14 reported being able to do things that they could not have done otherwise, e.g. taking their other children out, having a rest, shopping, and housework.” (p. 207)

“Families seem much more likely to use such services if they: are local and/or provide transport to and from the young person’s home; allow parents choice and flexibility; listen to what parents have to say both about the needs of their own young person and about the organization of the service more generally; emphasize the value of the service to the young people as well as the parents; and employ sufficient competent and caring staff.” (p. 210-211)

“All mothers preferred local services and, for six, it was very important usually because they did not have their own transport.” (p. (208)

McNally, S., Ben-Shlomo, Y. & Newman, S. (1999). Effects of respite care on informal carers' well-being: a systematic review. *Disability and Rehabilitation*, 21, (1), 1-14.

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Reviewed the literature on the effects of the provision of respite care on informal caregivers. Literature searches were performed using the PsycLit (1974-1997), Medline (1996-1997), and Social Science Citation Index (1996-1997) databases. The results yielded 29 studies, from which there was little evidence that respite intervention had either a consistent or enduring beneficial effect on caregivers' well-being. Of the 17 studies that focused on the effects of respite care on caregivers' psychological well-being, 10 reported improvements in psychological well-being, six reported no effects, and one found improvements only among caregivers caring for patients with a stable condition. It is argued that this may be due in part to the fact that the majority of the studies employed poor methodologies. Also significant may be that the findings suggest that respite care often fails to facilitate the maintenance of socially supportive relationships, which may moderate strain after respite has ended. (MM) (Ageline Database, copyright 1999 AARP, all rights reserved)

Of the 29 studies, 7 focused solely on caregivers of children (most of those studies are also addressed in this literature review). These studies were relatively small, with group sizes as follows: n=36, n=28/25, n=78, n=14, n=36, n=8, and n=26. Only one utilized a control group, comprised of families on a waiting list. A brief summary of the table of findings follows:

Study	Other outcomes/comments
Subramanian, 1985	none listed
Rimmerman, 1989	For many dimensions of the stress scale, reduction reached a peak at 12 months, showing some increase again at 18 months.
Rimmerman et al, 1989	Improvements only found in self-esteem, and only for mothers with high self-esteem and low functioning child.
Botuck and Winsberg, 1991	Improvements were found in well-being both during respite and for 3-4 days after respite.
Jawed et al, 1992	High career satisfaction.
Mausner, 1995	Less physician assistance was required after a year of the program.
Sherman, 1995	Decrease in somatic complaints by caregivers and in number of hospitalization days required by children.

Articles in this paper were selected for review only if they reported work assessing “the effects of respite intervention on informal careers (p. 8). “ Search terms included ‘respite’, ‘career’, ‘caregiver’, and ‘break’. In general, the authors found the research too methodologically poor.

“Problems such as a lack of control over variables that may have influenced findings, the absence of a control group, and insufficient sample sizes were common. In some cases, these problems were such that they would be likely to lead to the effects of respite being underestimated.” (p. 8)

One section of this article addresses the question: “Does respite intervention lead to improvements in careers’ well-being (p. 9)?” The most common and popular measures focused on psychological well-being. Ten of 17 studies focused on this found improvements. Three studies examined the impact of respite on physical health: two reported no effects of respite. The studies also were consistent in finding some improvement during and shortly after respite intervention, but “these improvements fail to endure for long after respite has ended (p. 9).”

“More recent studies (from 1992 onwards) seem to be more likely to show benefits from respite care than those in an earlier period (1985-1991)” (p. 11).

Citations referred to in the annotations above and cited with the article’s references:

Botluck S., & Winsberg, B.G., (1991). Effects of respite on mothers of school age and adult children with severe disabilities. *Mental Retardation*, 29; 43-47.

Jawed S.H., Krishman, V.H.R., & Oliver B.E., (1992). Respite care for children with mental handicap: Service evaluation and profile of children. *The British Journal of Mental Subnormality*; 74: 15-23.

Mausner, S. (1995). Families helping families: An innovative approach to the provision of respite care for families of children with complex medical needs. *Social Work in Pediatrics*, 95-106.

Rimmerman A.(1989). Provision of respite care for children with developmental disabilities: Changes in maternal coping and stress over time. *Mental Retardation*, 27: 99-103.

Rimmerman A., Kramer R., Levy, M., & Levy P.H. (1989) Who benefits most from respite care? *International Journal of Rehabilitation Research*, 12: 41-47.

Sherman, B.R., (1995) Impact of home-based respite care on families of children with chronic illnesses. *Children’s Health Care*, 24:33-45.

Subramanian, K. (1985). Reducing child abuse through respite center intervention. *Child Welfare*, 64: 510-509.

Miller, S.L., & Bortner, M. (1996). A week in the country: A model respite program. *AIDS Education and Prevention*, 8(2), 176-186.

This paper reports on a family-oriented camping program for caregivers of children who are HIV-positive. The program was designed to include medical care, social service, psychological and educational counseling, and training of volunteers in basic health care principles. The mental health needs of the population were also emphasized. Fifty percent of parents return year after year, taken as a positive outcome by the authors.

“The fact that families strive to maintain friendships that initially developed at camp with other families and to retain contact with camp staff long after camp is over, suggests that the benefits derived during camp should be reinforced on a continuing basis.” (p.185)

“As a generation of children born seropositive lives longer, as infected mothers’ lives are extended, and as AIDS spreads to expanding segments of the population, there will be a continuing and growing need for summer projects and for family support projects such as have been described here.” (p. 185)

[No author]. (1999). A conversation with Christine Gianopoulos. *Policy and Practice*, 57, (3), 32-36.

The director of Maine's Bureau of Elder and Adult Services was interviewed about Maine's approach to long-term care, which offers more choices and has succeeded in reducing the state's reliance on nursing home care and its related costs. These state-funded programs include respite for caregivers. Nursing facility spending is down 17%: "now, almost half the people are receiving care at home and a little over a third are receiving care in nursing facilities....our total long-term care is down 7% since 1995" (p. 33).

"For decades, states have relied almost exclusively on nursing homes to deliver long-term care services. Yet studies have shown that people prefer to remain in their homes and communities. This preference results in substantial savings to Medicaid because home care is generally less expensive than nursing home care." (p.32)

"We have definitely reduced our reliance on nursing home care, both in terms of dollars and numbers of people who are using nursing homes. We have expanded choices for consumers through the expansion of our home care programs and through a significant expansion in residential care and assisted living options." (p. 36)

Richey, C.I A. & Hodges, V. G. (1992). Empirical Support for the Effectiveness of Respite Care in Reducing Caregiver Burden: A Single-Case Analysis. *Research on Social Work Practice*, 2, (2), 143-160.

“This article examines the effectiveness of respite care in reducing feelings of entrapment and resentment experienced by a 69-year-old daughter who was sole caregiver for her frail, 99-year-old mother. Outcome measure collected weekly over a 2-month period included caregiver reports of amount and enjoyment of time away from home and attitude toward mother. An experimental single-system (ABAB) design allowed comparison of caregiver burden during times when respite care was and was not available. All measures evidenced statistically significant changes in predicted directions when respite care was in place. Issues discussed include operationalization of burden and the clinical significance of findings. The case study offers an example of how empirical support for respite care can be garnered to promote social welfare policies and programs that are responsive to the needs of families pursuing caregiving functions.”

“People are living longer, resulting in increasing numbers of older citizens. In the United States the proportion of people aged 65 years and over has doubled since the beginning of this century and is expected to triple within the early part of the next century (Sigel & Taeubex, 1982).” (p. 143)

“Caring for severely impaired older parents often begins when the caregiver is herself in middle age or early old age, thus marking the beginning of another “caregiving career (Briar & Ryan, 1986, p. 23) “. For example, a recent study of 50 caregivers and their frail relatives reported that 48% of the caregivers were adult daughters, and the mean caregiver age for the entire sample was 60.34 years (Marks, 1988).” (p. 145)

“Because family members providing continuous care make numerous personal sacrifices, it is not uncommon for intense, negative emotional reactions to develop, including bitterness about their situation (Doll, 1976) and resentment, hostility, and even violence toward the elderly person (Clark & Rakowski, 1983; Hickey & Douglass, 1981). When physical, economic, or emotional burdens reach intense levels, the caregiver’s recognition of and sensitivity and responsiveness to the needs of a frail elder are greatly reduced. Thus adult caretakers, overtaxed by caregiving demands, may be at greater risk for elder neglect and abuse (Hickey & Douglass, 1981).” (p. 145-146)

“Anne identified a number of specific strains, including her mother’s bladder incontinence and need for 24-hour supervision, resulting in Anne’s feeling “trapped,” “a prisoner in my own home.” Further assessment revealed that Anne typically experienced

many conflicting and troubling thoughts both when preparing to leave the house (e.g., “I need to get away” and “I shouldn’t leave Mom alone”) and when she was out of the house, even for a short time (e.g., “I should be home” and “I’m not a good daughter”). She reported experiencing high levels of tension and anxiety and low levels of enjoyment or satisfaction during these ventures away from home. Often she would return home earlier than originally planned, feeling tired, weepy, and resentful of Mom (e.g., “I feel cheated” and “I feel trapped”). Thus, for Anne, caregiver burden included feelings of entrapment and lack of freedom to leave her home, as well as resultant negative feelings about herself and her mother.” (p. 148)

“All three outcome measures, amount and enjoyment of time out of the house and attitude toward mother, evidenced rather dramatic changes in predicted directions when respite care was introduced, withdrawn, and reintroduced.” (p. 151)

“The unintended ABAB design in this case study supports the positive impact of respite care on caregiver burden.” (p. 155)

“Because the family will continue to play an important support role with vulnerable individuals, it is imperative that the material, social, and emotional strains placed on relatives be recognized and addressed programmatically.” (p. 157)

Citations referred to in the annotations above and cited with the article’s references:

Briar, K.H., & Ryan, R. (1986). The anti-institution movement and women caregivers. *Affilia*, 1(1), 20-31.

Clark, N.M., & Rakowski, W. (1983). Family caregivers of older adults: Improving helping skills. *Gerontologist*, 23, 637-643.

Doll, W. (1976). Family coping with the mentally ill: An unanticipated problem of deinstitutionalization. *Hospital and Community Psychiatry*, 27, 183-185.

Hickey, T., & Douglass, R.L. (1981). Mistreatment of the elderly in the domestic setting: An exploratory study. *American Journal of Public Health*, 71, 500-507.

Marks, R. (1988, June). Families with frail elderly: An examination of family life, mechanisms of support and long-term care policy. In E. Rayne (Ed.), *Families in transition: Implications for social work and practice* (Tulane Studies in Social Welfare Vol. 17, pp. 149-167). New Orleans: Tulane University.

Siegel, J.S., & Taeubex, C.M. (1982). The 1980 census and the elderly: New data available to planners and practitioners. *Gerontologist*, 22, 144-150.

Rimmerman, A., Kramer, R., Levy, J.M., & Levy, P.H. (1989). Who benefits most from respite care? *International Journal of Rehabilitation Research*, 12(1), 41-47.

This study examined the impact of respite care on mothers of mentally retarded children and adults who received in-home and center-based respite care. Questionnaires included instruments to measure stress, interpersonal response, and perception of family systems. They found that respite care did not generally enhance mothers' coping resources or reduce stress. Mothers with already high self esteem experienced greater benefits, and mothers of young children benefited more than those with older children.

Rimmerman, A. (1989). Provision of respite care for children with developmental disabilities: Changes in maternal coping and stress over time. *Mental Retardation*, 27(2), 99-103.

This article describes changes in maternal coping resources and stress over time as a consequence of the provision of respite care for their children with developmental disabilities. Matched groups of home-based respite care users and nonusers were compared. Respite services were shown to be associated with an immediate and significant reduction in maternal stress. Although over time some changes in coping resources and stress levels were reported, the respite care group showed overall consistent benefits as compared to those not receiving services.

In this study, home-based services were provided to the respite users group for at least 6 hours a week for 18 months. The instruments used to measure outcomes looked at four factors: Parent and Family Problems, Parental Pessimism, Parental Perception of Child's Characteristics, and Parental Perception of Child's Physical Incapacitation.

“In general, the research hypotheses were confirmed. Mothers who received 6 hours or more a week of respite services scored lower on parental and family problems, pessimism, and perception of child's burden (measured by parental perception of child's characteristics and physical incapacitation) .” (p. 101)

“The use of respite services brought the greatest degree of positive change in the way mothers perceived their children after the first 6 months of the study.” (p. 102)

Rudin, D. J. (1994). Caregiver Attitudes Regarding Utilization and Usefulness of Respite Services for People with Alzheimer's Disease. *Journal of Gerontological Social Work*, 23, 1-2, 85-107.

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Presents a literature review on caregivers' respite utilization as it is associated with and affected by caregiver's perceptions of respite availability, accessibility, quality/hospitality, and usefulness. The review included 12 research-based articles and six practice-based articles focusing on caregivers of those with Alzheimer's disease. Findings indicate that while caregivers may recognize the need for respite, these services may not be available to them. No such programs may exist in the community in which they live, and even if they do exist, they may not be open to patients at all levels of functioning, or scheduling may be a problem. Even if programs exist and openings are available, the program may not be conveniently located for the caregiver or the cost may be prohibitive. Other factors caregivers consider when deciding whether to use a service include characteristics of the program (its location, staffing, and program activities), which may create "social distance" between the service and the family. Also affecting utilization is the caregivers' views of the quality of the service and the patient's reaction to it. Caregivers judge the usefulness of a respite program on two criteria: what does it do for me and what does it do for the person for whom I am caring? Implications for program planning and service delivery are considered. Two tables profile study characteristics and the basic issues related to use and underutilization in each study. (WD) (*Ageline Database, copyright 1995 AARP, all rights reserved.*)

"Looman and Deimling (1991) asked caregivers about difficulties with both in-home and group respite and found that the top three problems related to scheduling." (p. 93)

"These findings indicate that proximity is not the sole criterion determining service utilization and, perhaps, what a service offers (such as socialization for patients in a congregate care program, or the opportunity for rural, isolated caregivers to meet other caregivers) may be an important aspect of the service." (p. 95)

"The data presented in this literature review indicate a number of areas for more in-depth exploration of caregiver choices and preferences regarding respite. Cost as it relates to caregivers' decisions to utilize services is inadequately addressed in most studies, despite the importance of caregiver reports of the impact of cost on the utilization of respite services." (p. 102)

"The extent to which patient preferences play a role in caregivers' decisions to utilize services is another essential area for future research." (p. 102)

“The data presented here also point to the need for more rigorous exploration of caregiver motivation in the selection of different types of respite. This would include how caregivers assess the potential benefits and drawbacks of each type of respite service (Larkin et al., 1988; Petchers et al, 1991) and how they decide which types of respite to use. Collins et al. (1991) have constructed a Community Service Attitude Inventory which includes many variables applicable to caregiver assessment of respite services, including ‘concern for opinion of others,’ and ‘confidence in service system.’ This instrument could be adapted to address many of the variables associated with respite utilization identified in this literature review.” (p. 102)

“As demonstrated by the fact that only 12 research-based articles were identified for this review, there is much room for new research on the role that caregiver preferences and beliefs play in the selection of respite services. Lawton et al. (1989b) concluded that, ‘caregivers show discriminating judgment in deciding whether to use [respite] services and the usual principles of consumer demand can probably be counted on to regulate the extent to which it is used...by those who need it” (p.15). For respite services, an essential part of gauging consumer demand is understanding the forces that drive caregivers to consider using respite, and the criteria by which they judge which services, if any, to use.” (p. 103)

Citations referred to in the annotations above and cited with the article’s references:

Collins, C., Stommel, M., King, S., & Given, C.W. (1991). Assessment of the attitudes of family caregivers toward community services. *The Gerontologist*, 31(6), 756-761.

Larkin, J., Rheume, Y., Selter, B., Brown J., Lyon, P, Fabiszewski, K., & Whitaker, J. (1988). An in-hospital respite program for Alzheimer’s, *The American Journal of Alzheimer’s Care and Related Disorders & Research*, 3(3) 26-30.

Lawton, M.P, Brody, E.M. & Saperstein, A.R. (1989b). Respite care for Alzheimer’s families: Research findings and their relevance to providers. *The American Journal of Alzheimer’s Care and Related Disorders and Research*, 4(6), 31-38.

Looman, W.J., & Deimling, G.T. (1991, November). *Patient resistance to participation in day care and in-home respite programs: The impact on caregiver benefits and service use*. Poster session presented at the 44th annual meeting of the Gerontological Society of America, San Francisco, CA.

Petchers, M.K., Biegel, D.E., & Snyder, A. (1991). *Barriers to implementation of a cooperative model of respite care*. *Journal of Gerontological Social Work*, 6(3/4), 17-31.

Sherman, B.R. (1995). Impact of home-based respite care on families of children with chronic illnesses. *Children's Health Care*, 24(1), 33-45.

This study evaluated whether respite care reduced stress and improved the quality of life for families caring for children with chronic illnesses. There was a statistically significant reduction in somatic complaints by primary caregivers and a decrease in the number of hospitalization days required by children. Data and results are well described. The majority of respondents reported significant relief from stress made possible by having the chance to do other activities than care giving. The operational definition of respite in this study refers to "home-based-skilled pediatric nursing, a service whose level of technological sophistication would be unparalleled in most other respite programs and consequently unavailable" (p.35).

"One promising approach is respite care or short-term relief for primary caregivers. Respite services that can be provided within the family's own home on their terms have the potential to result in positive social experiences for the child, family and provider." (p. 35)

"The dramatic medical advances of the past few decades have meant that many children, who would have died previously of their chronic illnesses, now survive into adulthood and live longer with their families in their home communities." (p.35)

"Some parents reported that the respite providers offered new approaches to providing better care for the children. Of primary benefit to the children with chronic illnesses, according to their parents, was the socialization experience with people outside the family as well as the instillation of trust in others." (p. 43)

"A precise fiscal analysis of a home-based respite program . . . is extremely difficult to undertake. Simply stated, one can begin to comprehend the tremendous cost effectiveness of the program if, for each day of respite service provided to the family of a medically fragile child, the need for 1 hospitalization day or additional outpatient or emergency room visit can be eliminated" (p. 43).

Sledge, W. H., Tebes, J., Wolff, N., & Heminiak, T. W., (1996). Day hospital/crisis respite care versus inpatient care, part I: Clinical outcomes. *The American Journal of Psychiatry*, 153(8), 1065-1073.

Note: Article was received electronically; page numbers for quotations unavailable.

This research team examined the clinical outcomes for urban, poor, acutely ill voluntary patients with severe mental illness who received treatment in a program designed as an alternative to hospitalization. This two year study found that the alternative program, a combined day hospital/crisis respite community residence, had the same treatment effectiveness as hospitalization. However, the alternative program was found to be generally less expensive. Patients were randomly assigned to receive day hospital/crisis respite or inpatient hospitalization. One hundred and four patients were treated in the inpatient hospital, while 93 received day hospital/crisis respite treatment.

Part II of the study describes the cost comparisons, while Part I focuses on clinical outcomes. Findings are generalizable to comparable clinical settings treating poor, severely disabled patients.

“The day hospital/crisis respite program tended to produce slightly stronger effects on psychiatric symptoms, global functioning, problems with living situation, and perceived need for help.”

“We were surprised by the lack of differences between the two programs in patient outcomes of symptoms, functioning, social adjustment, and quality of life.”

“We are left to conclude that in our setting, these two treatment options have roughly equal effectiveness.”

Sledge, W.H., Tebes, J., Wolff, N., & Helminiak, T.W. (1996). Day hospital/crisis respite care versus inpatient care, part II: Service utilization and costs. *The American Journal of Psychiatry*, 153(8), 1074-1083.

Note: Article was received electronically; page numbers for quotations unavailable.

This article is the second part of a study that compared outcomes for acutely ill psychiatric patients treated in day hospital/crisis respite programs versus hospital inpatient programs. The programs were found to be equally effective, but day hospital/crisis respite treatment was found to be generally less expensive. Cost savings were found to be higher for non-psychotic patients. Differences are driven by the hospital's higher overhead costs.

On average, the day hospital/crisis respite program showed a savings of \$7,100, or 20% of total costs of treatment. This treatment option had operating costs of 51% of inpatient hospital costs.

“Roughly equal expenditures for direct service staff costs in the two programs may be an important clue for understanding why these programs provided equally effective acute care.”

“It is no longer sufficient for treatments to be effective; they must also be cost-effective.”

“Our experimental treatment program . . . was found to be as effective (or slightly more so), on the basis of standardized clinical and patient assessment measures, as hospital care for the voluntary patients who met the admission criteria.”

“It may be possible to lower treatment costs by providing the same services (as an inpatient setting) in more specialized, decentralized environments that have lower overhead costs.”

“Hospitalizing most voluntary patients with uncomplicated psychiatric distress cannot be defended on the grounds of either effectiveness or cost.”

“Many people with major mental illnesses can be treated safely and effectively with substantially less expense in settings that provide the essential functions of a hospital without some of the nonessential functions that carry high operating costs.”

“Our findings suggest that the use of a crisis residence provides flexibility in effectively matching patients to a program that offers the intensity of services that best meets their clinical needs and improves the overall efficiency of the mental health delivery system.”

“Developing care in lower-cost settings to substitute for hospital care offers a mechanism for expanding the purchasing value of mental health dollars without placing the patient's mental health at risk.”

Strang, V.R., & Haughey, M. (1999). Respite — A coping strategy for family caregivers. *Western Journal of Nursing Research*, 21(4), 450-471.

This interpretive research study explored how 10 family caregivers of persons with dementia experienced respite. The article looks closely at the emotional and cognitive shifts involved in a caregiver's decisions to use respite and to benefit from the experience. The author cautioned that due to a lack of ethnic, educational and financial diversity in the sample, it is difficult to generalize the findings to all social groups. It was found that the quality of the respite experience was more important than the duration, although longer respite intervals, usually associated with institutional respite, led to a sense of recuperation or 'recharging of batteries'.

The experience of respite included three cognitive phases for the caregivers:

“recognizing the need to get out of the caregiver world; giving themselves permission to get away from caregiving responsibilities for a while (and realizing that such self-serving behavior was appropriate); and finally, realizing the availability and adequacy of social supports that would allow them to get away.” (p.455)

“Study findings suggest that nurses and others must be aware that the provision of a respite service does not necessarily result in a respite experience for caregivers. There must be a recognition that the service, whether it provides shorter or longer respite intervals, be provided in such a way that caregivers feel free from the regular worry and hassle associated with the caregiving world.” (p. 463)

Subramanian, K., “Reducing Child Abuse Through Respite Center Intervention” *Child Welfare*, 64(5): 501-509, Copyright 1985, Child Welfare League of America.

This article summarizes the results of a research project that studied the effects of emergency respite (Crisis Care) on parental stress. The article discusses risk factors for child maltreatment and describes how parental stress, when combined with certain risk factors, significantly increases the degree of risk to the child. The findings supported the concept that emergency respite care can have a mediating effect on risk of child abuse and neglect.

“Emergency respite care for children is shown to be effective in reducing stress on parents that can result in child abuse.” *Reprinted by special permission of the Child Welfare League of America, Washington, DC* <<http://www.cwla.org>>.

“Potentially abusive parents must have relief systems available to them at critical moments of stress, yet they often view social service agencies as threatening. At these times, the concept of community-based respite care is a major innovation designed to prevent child abuse.” (p. 501)

“Although emergency or crisis-oriented child care is thought to be particularly crucial in preventing child abuse [Cohn 1981], the literature concerning respite care as an emergency child care service is sparse and there are no studies to evaluate the effectiveness of these centers.” (p. 502)

“Emergency or crisis-oriented child care is thought to be particularly crucial in preventing child abuse [Cohn 1981].” (p. 503-504)

“Unlike shelters where children are taken after they have been harmed, respite centers aim to separate children and parents at times when parents might feel like taking out their frustrations on their children.” (p. 504)

“If most people believe that the family unit provides the most beneficial environment for rearing and nourishing children and for equipping them with values, a primary concern of any preventive strategy should be strengthening the family, and specific programs should strive to reinforce parent-child relationships that allow the family to function as an independent unit.” (p. 504)

“Respite care fulfills this criterion by being a form of home-based care in which help is available before the last resort is reached.” (p. 504)

Subramanian, K., “Reducing Child Abuse Through Respite Center Intervention” *Child Welfare*, 64(5): 501-509, Copyright 1985, Child Welfare League of America. (continued)

“The primary goal of this study was to determine the degree to which parental stress was reduced by respite care. A second goal was to evaluate the relationship of respite care to the prevention of abuse and neglect; it was hypothesized that the parents using respite care have characteristics that, when affected by stress, may result in abuse and neglect.” (p. 504-505)

“The analysis of the “Levels of Stress” scales show a significant reduction, after the receipt of respite care, in all affective and overall measures of stress except on the “Fatigue” variable.” (p. 508)

“This study lends support to the belief that emergency respite care is serving as a preventive service for child abuse.” (p. 509)

“Respite services, whether direct or indirect, seem helpful in reducing the stress that is associated with these abusive situations, and in providing either counseling or referral for life crises that have not yet been fully resolved.” (p. 509)

Citation referred to in the annotations above and cited with the article’s references:

Cohn, A. H.(1981) *An Approach to Preventing Child Abuse*. Chicago, IL: National Committee for the Prevention of Child Abuse.

Theis, S.L., Moss, J.H., & Pearson, M.A. (1994). Respite for caregivers: An evaluation study. *Journal of Community Health Nursing*, 11(1), 31-44.

This evaluation study, using quantitative analysis, aimed to learn the effect of respite on family caregivers of the elderly in the areas of quality of life, mood, and response to care giving. Additionally, the study looked for benefits of respite other than the ones being directly measured. Caregivers were given up to 4 hours of respite per week. Short-term institutional respite was also available. The in-home providers were volunteers trained and supervised by nurses. Subjects were 130 caregivers, with 6- and 12-month data on a smaller sub sample. Instruments used to measure outcome variables included: The Family Inventory of Resource Management (FIRM: McCubbin and Thompson, 1987), the Profile of Mood States (McNair, Lorr, & Droppelman, 1981), and The Quality Of Life Index (Ferrans & Powers, 1985).

No statistically significant changes on the measures were found although the caregivers expressed great satisfaction with the service. During the time the study was conducted, the health of the care recipients declined. It was suggested that to more accurately assess outcomes, this factor should be considered.

Caregivers displayed overwhelming satisfaction with respite: 64% improved their physical health, and 78% improved their emotional health. Fifty percent cited improvement in the care recipient as well. Forty percent stated they were less likely to institutionalize the care recipient because of the respite they had received. There is a great deal more data on changes according to specific data measures.

“Because of the declining health status of care recipients, it is interesting that scores on the instruments did not change statistically. It could be that respite did play a part in moderating the effects of caregiving or that caregivers learn to cope as time progresses.” (p. 42)

Typical caregiver responses included

“Respite conditioned me quite effectively to accepting care in and out of the home [eventually knowing when nursing home placement was necessary].” (p. 37)

“Most people [and programs] dwell on the patient and what the patient needs and they overlook the one that’s doin’ all the work.” (p. 37)

Citations referred to in the annotations above and cited with the article’s references:

Theis, S.L., Moss, J.H., & Pearson, M.A. (1994). Respite for caregivers: An evaluation study. *Journal of Community Health Nursing*, 11(1), 31-44. (continued)

Ferrans, C. E., & Powers, M.J. (1985). Quality of Life Index: Development and psychometric properties. *Advances in Nursing Science*, 8, 15-24.

McCubbin, H. I., & Thompson, A. I., (1987). *Family assessment inventories for research and practice*. Madison: The University of Wisconsin.

McNair, D.M., Lorr & Droppelman, L.F. (1981). *Profile of Mood States manual*. San Diego: Educational and Industrial Testing Service.

Wikler, L.M., Hanusa, D., & Stoycheff, J. (1986). Home-based respite care, the child with developmental disabilities, and family stress: Some theoretical and pragmatic aspects of process evaluation. In C.L. Salisbury & J. Intagliata's *Respite Care: Support for Persons With Developmental Disabilities and Their Families*.

Some of the literature on family stress is summarized in this chapter. The chapter also suggests ways in which respite care may alleviate stress. Finally, it describes how two prevention-oriented respite care programs conducted by the authors were evaluated. Their evaluations used pre-and post-measures as well as process evaluation in order to fully describe various features of respite care.

Both programs studied provided a minimum of 6 hours of respite per week to families of children with developmental disabilities. One served families with children who had recently been returned to the community but because of behavioral problems, were at risk for reinstitutionalization. The second served families who were committed to keeping their children at home and had volunteered to receive respite. The stress levels of both sets of families were monitored throughout the time the families received respite.

In the first program, monitoring the behavioral problems of the handicapped child was the focus. Parents reported high satisfaction, but varied in their responses on stress levels. Case descriptions of the children were given. The children showed maintenance and improvement in several areas (obedience of commands, increase in verbalizations, fewer temper tantrums). Maintenance and prevention of deterioration is surely a worthy outcome for children and their parents. Over the four-month period of respite “none of the families requested readmission of their child (to an institution)” (p. 249).

In the second program, no specific behavioral program for the children was developed; the focus was on providing relief to the parents. Post-respite, the parents rated the reduction in family stress due to respite care. “They assessed their own overall stress reduction as a 4.00 out of a possible 5” (p.254).

Of 10 families selected for the slots in the project, only two cases were described in this chapter. The mother of one of the children said, “Worry free fun temporarily made me feel less stressed and able to face the world every day without becoming bogged down in grief” (p. 251). For the first time ever, this mother reported feeling comfortable leaving her child with a non-relative. Another mother reported considerable decrease in stress after respite, improved relationship with the child, and that her (the child's) behavior was much better.

Wikler, L.M., Hanusa, D., & Stoycheff, J. (1986). Home-based respite care, the child with developmental disabilities, and family stress: Some theoretical and pragmatic aspects of process evaluation. In C.L. Salisbury & J. Intagliata's *Respite Care: Support for Persons With Developmental Disabilities and Their Families*. (continued)

“Significant change was observed in the negative attitudes toward the child with developmental disabilities. Observing their child interacting pleasantly with another adult, as well as seeing another person manage the youngster’s difficult behaviors, may alter their own attitudes and energy in subsequent interactions with that child.” (p. 256)

“When families with children who are developmentally disabled are asked to name services that would be helpful to them, respite care is usually mentioned first.” (p.243)

Zarit, S. H., Leitsch, S.A. (2001). Developing and Evaluating Community Based Intervention Programs for Alzheimer’s Patients and Their Caregivers. *Aging and Mental Health*, 5, (1), S84-S98. Reprinted with permission of Ageline.

Explicates the benefits of a systematic approach to the design and evaluation of intervention programs for Alzheimer’s disease (AD) patients and their caregivers. Uses examples from existing literature as a vehicle to address the important conceptual and methodological issues related to AD interventions. Includes examples both from successful and unsuccessful programs. Maintains that it is critical that interventions evaluate the anticipated outcomes for both the caregiver and the person with AD. Stresses the need for design and evaluations that apply creative and robust treatments but do not compromise scientific rigor. Argues that the goals, design, and evaluation of interventions for people with dementia and their caregivers need to reflect the degenerative course of the disease and the unique strain experienced by family caregivers. Considers the goals and needs of the caregiver-care recipient dyad, as well as the larger social context in which they are embedded. Examines issues in the design of successful interventions, such as goals and magnitude of treatment. Looks at evaluation strategies specific to caregiver research, such as the choice of measures sensitive to change and the advantages and disadvantages of different types of control conditions. Concludes that community-based interventions are promising and that programs of individual and family counseling and respite interventions lower stress on family caregivers. (AR) (*Ageline Database, copyright 2001 AARP, all rights reserved.*)

“Respite care (a social resource) can provide relief by reducing exposure to stressors.”
(p. S87)

“Brodaty and Peters (1991) found that a 10-day intensive residential program for people with dementia and their caregivers increased the length of time the person with dementia was able to remain at home and decreased morbidity among caregivers. The results showed a cost savings of nearly US\$6000 per family over a 39-month period, largely as a result of delaying placement.” (p. S94)

“...community-based interventions have shown promising results. Programs of individual and family counseling and respite interventions that provided adequate amounts of help have been found to lower stress on family caregivers.” (p. S96)

Citation referred to in the annotations above and cited with the article’s references:

Brodaty, H. & Peters, K.E. (1991). Cost effectiveness of a training program for dementia carers. *International Psychogeriatrics*, 3, 11-22.

Zarit, S. H., Gaugler, J. E. & Jarrott, S. E. (1999). Useful Services for Families: Research Findings and Directions. *International Journal of Geriatric Psychiatry*, 14, (3), 165-181.

Reprinted with permission of Ageline.

Reviews the literature on the benefits of community-based services for family caregivers and frail older adults with physical disabilities and/or dementia. Evidence of the benefits of community-based services is examined from four perspectives: relief for family caregivers, benefits to older clients, delay or prevention of institutionalization, and cost-effectiveness or cost benefits of a service. Studies are grouped according to the type of service (in-home respite, adult day care, overnight respite, case management, and multicomponent programs) and type of clients (dementia only or mixed). The authors report surprisingly few empirical studies overall and conclude that the reported benefits are typically modest. Methodological problems and limited provision of service may have accounted for these findings. Studies in which clients and their families received adequate amounts of help showed more consistently positive outcomes. There is little evidence to suggest that community services delay placement in nursing homes. (WD) (*Ageline Database, copyright 1999 AARP, all rights reserved.*)

“Caregivers who used ADS on a regular basis (2 days a week or more) for at least 3 months had significantly lower levels of care-related stressors (eg feelings of overload and strain) than controls, as well as lower feelings of depression and anger. Benefits were still apparent after 1 year, with the treatment group having lower feelings of overload and depression than controls.” (p. 167)

“... the benefits of overnight respite were reviewed as transitory.” (p. 168)

“...the negative effects of caring for someone with behavior problems was reduced when caregivers used more personal care services. Personal care services also had smaller but significant moderating effects on the relation of behavioral problems to caregivers’ health and social isolation.” (p. 168)

“Benefits to caregivers are most likely to be found with regular, sustained use of respite. However, a consistent theme across these studies is that caregivers do not always avail themselves of appropriate services.” (p. 168-169)

Zarit, S. H., Gaugler, J. E. & Jarrott, S. E. (1999). Useful Services for Families: Research Findings and Directions. *International Journal of Geriatric Psychiatry*, 14, (3), 165-181. (continued)

“After 5 months of using ADS, caregivers reported that the day program provided stimulation and activities for the patient which resulted in improved mood and increased engagement in activities. The opportunity to get out of the house and to socialize with others was also noted. Many caregivers reported that their relatives greatly looked forward to attending the ADS program.” (p. 169)

“Specifically, family caregivers received emotional and instrumental support from a trained home-health aide for a 10-week period. There were significantly fewer admissions to a nursing facility or retirement home among the treatment group than the control group.” (p. 170)

“...findings suggest that a moderate investment in an in-home support program may be effective in maintaining an elderly relative in the community for longer periods of time.” (p. 170)

“...the direction of results from the available research does not suggest that overnight respite delays permanent placement. Indeed, it may facilitate placement by helping caregivers break their emotional bonds or overcome their apprehension about the care their relative would receive in a nursing home.” (p. 171)

“...programs that have had successful outcomes have usually provided adequate amounts of assistance.” (p. 174-175)

“Only those interventions that substantially alter the caregiver’s exposure to stressors can be expected to provide meaningful relief. “ (p. 175)

Zarit, S. H., Parris Stephens, M. A. Townsend, A., Greene R, & Leitsch, S. A. (1999). Patterns of Adult Day Service Use by Family Caregivers: A Comparison of Brief versus Sustained Use. *Family Relations*, 48, (4), 355-361.

Reprinted with permission of Ageline.

Examined patterns of adult day services (ADS) use by family caregivers to persons with dementia. Seventy-two caregivers (mean age 65.35) who used ADC for a brief period of time (less than 3 months) and 93 caregivers (mean age 55.65) who used ADS for a sustained period (more than one year) were studied. Variables measured included sociodemographic characteristics, primary caregiver stressors, perceived impact that the stressors had on the caregiver's life, caregiver well-being, and factors related to care received after discharge from the ADS program. Data on all but the last variable were gathered as part of a larger study during an initial interview at the time caregivers enrolled their relative in an ADS program. Discharge-related data were gathered by telephone interviews postdischarge with ADS staff and the caregivers. Results indicate that caregivers whose relative used ADS briefly were more likely to be spouses, had less education, and were caring for more severely impaired relatives than sustained users. They were also experiencing more role captivity (the extent to which they were felt trapped and constrained in the caregiving role) but fewer depressive symptoms and more positive affect. The results suggest that brief users have often waited until their relative's problem is severe before trying ADS. (KM) (*Ageline Database, copyright 1999 AARP, all rights reserved.*)

“One of the most critical issues in developing interventions for family caregivers is that rates of service use are relatively low, despite considerable apparent need. Since ADS lowers stress and improves well-being for family caregivers who use it for three months or more (Zarit et al., 1998), it is particularly important to clarify why some people choose not to continue in these programs.” (p. 360)

“The present findings may reflect that caregivers with higher initial depression scores (after adjusting for other variables) may have been more likely to use ADS on a sustained basis because they got some relief from their depressive symptoms. It may also be that caregivers can justify the use of respite services if they are experiencing emotional distress.” (p. 361)

“As the present study shows, a sizable minority among service users use ADS only very briefly. It may be that their relative is already too difficult to manage, or because, attitudinally, these caregivers find it difficult to accept this type of help.” (p. 361)

Zarit, S. H., Parris Stephens, M. A. Townsend, A., Greene R, & Leitsch, S. A. (1999). Patterns of Adult Day Service Use by Family Caregivers: A Comparison of Brief versus Sustained Use. *Family Relations*, 48, (4), 355-361. (continued)

“Earlier intervention, as well as identifying more clearly the obstacles that caregivers face in using ADS and other respite services, might also expand the proportion of caregivers who can get relief from these programs.” (p. 361)

Citation referred to in the annotations above and cited with the article’s references:

Zarit, S.H., Stephens, M.A., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology: Social Sciences*, 53B, S267-S277.

Zarit, S.H., Parris Stephens, M.A., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of adult day care use. *The Journals of Gerontology*, 53B(5), S267-S277.

Note: Article was received electronically; page numbers for quotations unavailable.

The findings of an evaluation of the psychological benefits of using adult day-care for caregivers of relatives with dementia are reported in this article. A quasi-experimental design was used. In the treatment group, caregivers received substantial amounts of day care (at least 2 days per week), whereas caregivers in a control group did not use day care at any point in the evaluation. The authors clearly delineate the previous literature and the multiple shortcomings of earlier studies on the effects of day care. This study was designed to address the limitations of prior research. Of 445 individuals screened for eligibility, 261 were eligible and interviewed at the start of the study (T1).

“The results of this evaluation demonstrate that caregivers of relatives with dementia who use adult day care experience lower levels of care giving-related stress and better psychological well-being than a control group not using this service. These differences are found in both short-term (3 months) and long-term (12 months) users.”

“As predicted, using adult day care resulted in ‘lower feelings of overload and worry/strain.’”

“Depression is a significant mental health problem for caregivers of dementia patients. Our study showed that caregivers using adult day care experienced lower anger than controls at 3 months and less depression than controls at 3 months and 1 year.”

“...these findings indicate that day care results in better psychological functioning for service users than for controls.”