



Annotated Bibliography of Respite and Crisis Care Studies, 5th Edition

2020

ARCH National Respite Network
and Resource Center

**Lifespan Respite
Technical Assistance Center**



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Introduction

Respite is generally accepted to be an important component of a comprehensive strategy to support family caregivers and care recipients and this is supported in the literature. However, a stronger evidence base is both desirable and necessary to recognize respite as a core component of a comprehensive strategy to support family caregivers, to merit funding for respite, demonstrate continuous quality improvement, and to identify and replicate respite best practices. This updated annotated bibliography adds ten new articles to the 4th edition bibliography published by ARCH in 2018, reflecting an ongoing interest among researchers to better identify the effects of respite on caregiver, care recipient, family and societal outcomes, and strengthening the evidence base.

Several of the studies added to this edition of the bibliography examine informal respite supports, such as family and friends and volunteer respite, and compare them to formal supports. These studies are especially relevant, given that we are now in the midst of the COVID-19 pandemic, and formal respite supports, especially adult day care and other community-based respite services, are unavailable for many families. Study findings indicate that informal supports can provide meaningful respite for family caregivers. Leggett and colleagues employed a cross-sectional study design using secondary data from the National Study of Caregivers (NSOC) and found that caregivers of people with dementia who provided more assistance with activities of daily living and had friends and family to talk to, reported more caregiving gains than those who did not have support from friends and family (Leggett, et al., 2020). Another study from the Netherlands compared support from family and friends, from other informal supports including volunteers, and respite from professional home care providers. The researchers found that professional home care and support from family and friends both result in caregivers spending fewer hours providing care, which moderates the difficulties of caregiving and improves caregivers' feelings of well-being. At the same time, the authors acknowledge that receipt of supports from other informal caregivers and volunteers was not strongly associated with improvements for caregivers and that this finding has important policy implications (Verbakel, et al., 2018). It is encouraging that these studies found that in-home respite as well as informal supports, especially from family and friends, can help mitigate caregiving stressors.

While these new studies are promising, every study author cites limitations in their research that often result in the inability to draw very strong conclusions about respite cause and effect. We are still in need of more information to document how and to what extent respite may affect the health and well-being of family caregivers and care recipients, family relationships and stability, family economic well-being, the rate and timing of out-of-home placements, and other possible health, social and economic outcomes. While research has demonstrated that respite holds significant promise when it is part of a multicomponent

intervention strategy to support caregivers, we still have much to learn about what types of respite family caregivers and care recipients prefer and are most beneficial, where needs and gaps in services exist, and how to improve access to and quality of services.

Where to do we go from here?

The ARCH Expert Panel on Respite Research developed a research agenda published in 2014 to guide the development of a stronger evidence base for respite. In an attempt to implement the Panel's recommendations, ARCH continues to build a Respite Research Consortium with the goal of linking researchers to funding sources to encourage more high quality research that will lead to a better understanding of the value of respite to family caregivers, care recipients, their families, and communities and how to improve service delivery, service models, and access. This updated bibliography is intended to inform this work by highlighting new research findings and by continuing to identify research gaps and limitations where they exist. Several researchers cited in the bibliography are working with ARCH to help develop or advance research proposals or are currently undertaking studies utilizing the expert panel's research framework and guidance.

The literature review for this updated bibliography adds summaries of eleven peer-reviewed journal articles. Articles were included primarily from the time period 2018, where the 4th edition left off, through 2020. Studies were included if they documented outcomes of respite care for family caregivers, care recipients, families or communities. Relevant articles were included regardless of sample size and research methods used (e.g., studies using qualitative and/or quantitative data collection techniques, case studies, and cross-sectional, quasi-experimental or experimental study designs).

The next phase of ARCH's work to advance the respite research agenda will include: examination of how to improve access to and quality of respite services; identification of aspects of respite services and models that make them exemplary; encouragement of evaluation and replication of promising services; and translation of research findings into practice. ARCH is pleased to announce the formation of the ARCH Committee for Advancement of Respite Research (CARR) that will be charged with leading this effort and identifying additional goals [1]. Given the current effects of COVID-19 on respite service delivery, another focus of the Committee will be to identify methods for evaluating the impact of alternative respite options that are being developed to support family caregivers during the pandemic.

[1] List of the ARCH Committee for Advancement of Respite Research Members – <https://archrespite.org/CARR>

ARCH also collaborates with the University of Wisconsin-Madison School of Nursing [BREAK \(Building Respite Evidence and Knowledge\) Exchange](#), an international group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidence-based respite care [2]. Through this collaboration, ARCH will link respite services we identify as [Innovative and Exemplary](#) by a rigorous national application and selection process to interested researchers worldwide [3].

Organization of Bibliography

The article summaries are grouped into the following seven areas: 1) respite targeted to children; 2) respite targeted to older adults; 3) respite targeted to adults with developmental disabilities; 4) respite targeted to multi-age groups; 5) caregiver support for Veterans and their caregivers; 6) literature reviews/meta-analyses of respite care studies; and 7) methodological issues in research on respite and caregiver interventions.

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

Acknowledgements

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[2] BREAK Exchange – <https://breakexchange.wisc.edu/>

[3] ARCH Innovative and Exemplary Respite Services – <https://archrespite.org/innovative-and-exemplary-respite>

List of Articles for ARCH Annotated Bibliography

I. Studies of the outcomes of respite targeted to children

1. Aniol, K., Mullins, L.L., Page, M.C., Boyd, M.L., and Chaney, J.M. (2004). The relationship between respite care and child abuse potential in parents of children with developmental disabilities: A preliminary report. *Journal of Developmental and Physical Disabilities*, 16 (3): 273-285.
2. Barnard-Brak, L. and Thomson, E.D. (2009). How is taking care of caregivers of children with disabilities related to academic achievement? *Child Youth Care Forum*, 38: 91-102.
3. Cole, S.A., Wehrmann, K.C., Dewar, G. and Swinford, L. (2005). Crisis nurseries: Important services in a system of care for families and children. *Children and Youth Services Review*, 27 (9): 995-1010.
4. Cole, S.A. and Hernandez, P.M. (2008). Crisis nursery outcomes for caregivers served at multiple sites in Illinois. *Children and Youth Services Review*, 30: 452-465.
5. Cole, S.A. and Hernandez, P.M. (2011). Crisis nursery effects on child placement after foster care. *Children and Youth Services Review*, 33: 1445-1453.
6. Collins, M., Langer, S., Welch, V., Wells, E., Hatton, C., Robertson, J., and Emerson, E. (2013). A Break from Caring for a Disabled Child: Parent Perceptions of the Uses and Benefits of Short Break Provision in England. *British Journal of Social Work*, 26 (4): 271-83.
7. Cowen, P. and Reed, D. (2002). Effects of respite care for children with developmental disabilities: evaluation of an intervention for at-risk families. *Public Health Nursing*, 19 (4): 272–283.
8. Davies, B., Steele, R., Collins, J., Cook, K., and Smith, S. (2004). The impact on families of respite care in a children's hospice program. *Journal of Palliative Care*, 20 (4): 277-286.
9. Harper, A., Dyches, T.T., Harper, J., Roper, S.O., and South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43 (11): 2604-2616.
10. Mandell, D.S., Ming Xie, M.S., Morales, K.H., Lawer, L., McCarthy, M., and Marcus, S.C. (2012). The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Arch Pediatr Adolesc Med*, 166 (1): 68-73.
11. McConkey, R., Gent, C., and Scowcroft, E. (2013). Perceptions of Effective Support Services to Families with Disabled Children whose Behavior is Severely Challenging: A Multi-Informant Study. *J Appl Res Intellect Disabil*, 26 (4): 271-83.
12. Meltzer, J. and Johnson, S. B. (2004). Summer camps for chronically ill children: a source of respite care for mothers. *Children's Healthcare*, 33 (4): 317-331.
13. Mullins, L.L., Aniol, K., Boyd, M. L., Page, M.C., and Chaney, J.M. (2004). The influence of respite care on psychological distress in parents of children with developmental disabilities: a longitudinal study. *Children's Services: Social Policy, Research, And Practice*, 5 (2): 123-138.

14. Olsen, R. and Maslin-Prothero, P. (2001). Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: evidence from an evaluation. *Journal of Advanced Nursing*, 34 (5): 603-610.
15. Owens-Kane, S. (2007). Respite Care: Outcomes for Kinship and Non-Kinship Caregivers. *Journal of Health & Social Policy*, 22 (3/4): 85-99.
16. Pascuet, E., Cowin, L., Vaillancourt, R., Splinter, W., Vadeboncoeur, C., Dumond, L.G., Ni A., and Rattray, M. (2010). A comparative cost-minimization analysis of providing pediatric palliative respite care before and after the opening of services at a pediatric hospice. *Healthcare Management Forum*, 23 (2): 63-66.

Added in 2018

1. Crampton, D. and Yoon, S. (2016). Crisis nursery services and foster care prevention: An exploratory study. *Children and Youth Services Review*, 61: 311-316.
2. Dyches, T.T., Christensen, R., Harper, J.M., Mandleco, B., and Roper, S.O. (2016). Respite care for single mothers of children with autism spectrum disorders. *J Autism Dev Disord*, 46: 812-824.
3. Madden, E.E., Chanmugam, A., McRoy, R.G., Kaufman, L., Ayers-Lopez, S., Boo, M., and Ledesma, K. J. (2016). The impact of formal and informal respite care on foster, adoptive, and kinship parents caring for children involved in the child welfare system. *Child Adolesc Soc Work J*, 33: 523-534.
4. Remedios, C., Willenberg, L., Zordan, R., Murphy, A., Hessel, G. and Philip, J. (2015). A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. *Palliative Medicine*, 29 (3): 223-230.

Added in 2020

1. Eddy, J.M., Shortt, J.W., Martinez, C.R., Holmes, A., Wheeler, A., Gau, J., Seeley, J. Grossman, J. (2020). Outcomes from a randomized controlled trial of the Relief Nursery program. *Prevention Science*, 21: 36-46.
2. Norton, M., Dyches, T.T., Harper, J.M., Roper, S.O., & Caldarella, P. (2016). Respite care, stress, uplifts, and marital quality in parents of children with Down syndrome. *Journal of Autism and Developmental Disorders*. doi: 10.1007/s10803-016-2902-6

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

1. Carretero, S., Garces, J., and Rodenas, F. (2007). Evaluation of the Home Help Service and its impact on the informal caregiver's burden of dependent elders. *Int J Geriatr Psychiatr*, 22 (8): 738-49.
2. Empeño, J., Raming, N.T., Irwin, S.A., Nelesen, R.A., and Lloyd, L.S. (2011). The hospice caregiver support project: Providing support to reduce caregiver stress. *Journal of Palliative Medicine*, 14 (5): 593-597.
3. Fernia, E.E., Zarit, S.H., Stephens, M.A., and Greene, R. (2007). Impact of adult day services on behavioral and psychological symptoms of dementia. *The Gerontologist*, 47 (6): 775-788.

4. Gaugler, J.E., Jarrott, S.E., Zarit, S.H., Stephens, M-A.P., Townsend, A., and Greene, R. (2003). Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry*, 18 (1), 55–62.
5. Gitlin, L.N., Reeve, K., Dennis, M.P., Mathieu, E., and Hauck, W.W. (2006) Enhancing quality of life of families who use adult day services: short- and long-term effects of the Adult Day Services Plus Program. *The Gerontologist*, 46 (5): 630-639.
6. Hancock, P.J., Jarvis, J.A., and L'Veena, T. (2007). Older Carers in Ageing Societies: An Evaluation of a Respite Care Program for Older Carers in Western Australia. *Home Health Care Services Quarterly*, 26 (2) 2007, 59-84.
7. Lee, D., Morgan, K., and Lindsay, J. (2007) Effect of institutional respite care on the sleep of people with dementia and their primary caregivers. *J. Am. Geriatr Soc.*, Feb; 55(2): 252-8.
8. LaVela, S.L., Johnson, B. W., Miskevics, S. and Weaver, F.M. (2012). Impact of a multicomponent support services program on informal caregivers of adults aging with disabilities. *Journal of Gerontological Social Work*, 55: 160-174.
9. Lund, D.A., Utz, R. , Caserta, M.S., and Wright, S.D. (2009). Examining What Caregivers Do During Respite Time to Make Respite More Effective. *Journal of Applied Gerontology*, 28 (1): 109-131.
10. Mavall, L. and Thorslund, M. (2007). Does day care also provide care for the caregiver? *Arch Gerontol Geriatr*. Sep-Oct; 45(2): 137-50.
11. Neville, C.C. and Byrne, G.J. (2006) The impact of residential respite care on the behavior of older people. *Int Psychogeriatr*, 18 (1): 163-70.
12. Perry, J. and Bontinen, K. (2001). Evaluation of a weekend respite program for persons with Alzheimer Disease. *Can J Nurs Res*, 33: 81–95.
13. Schmitt, E.M., Sands, L.P., Weiss, S., Dowling, G., and Covinsky, K. (2010). Adult Day Health Center Participation and Health-Related Quality of Life. *The Gerontologist*, 50(4): 531-540.
14. Smeets, S.M., van Heugten, C.M., Geboers, J.F., Visser-Meily, J.M., and Schepers, V.P. (2012). Respite care after acquired brain injury: the well-being of caregivers and patients. *Arch Phys Med Rehabil*, 93 (5): 834-41.
15. Tompkins, S.A. and Bell, P. A. (2009). Examination of a psychoeducational intervention and a respite grant in relieving psychosocial stressors associated with being an Alzheimer's caregiver. *Journal of Gerontological Social Work*, 52 (2): 89-104.
16. Utz, R.L., Lund, D.A., Caserta, M.S., and Wright, S.D. (2012). The Benefits of Respite Time-Use: A Comparison of Employed and Nonemployed Caregivers. *Journal of Applied Gerontology*, 31: 438-461.
17. Warren, S., Kerr, J.R., Smith, D., and Schalm, C. (2003). The impact of adult day programs on family caregivers of elderly relatives. *J Community Health Nurs*, 20(4): 209-21.
18. Whitlatch, C.J. and Feinberg, L.F. (2006). Family and Friends as Respite Providers. *Journal of Aging & Social Policy*, 18 (3-4): 127-139.
19. Zarit, S.H., Kim, K., Femia, E.E., Almedia, D.M., Savla, J. and Molenaar, P.C.M. (2011). Effects of Adult Day Care on Daily Stress of Caregivers: A Within-Person Approach. *JGerontol B Psychol Sci Soc Sci*, 66 (5): 538–546.

20. Zarit, S.H., Kim, K., Femia, E.E., Almeida, D.M., Klein, L.C. (2014). The Effects of Adult Day Services on Family Caregivers' Daily Stress, Affect, and Health: Outcomes from the Daily Stress and Health (DaSH) Study. *The Gerontologist*, Vol 54, Issue 4, pages 570-579.
21. Zarit, S.H., Whetzel, C.A., Kim, K., Femia, E.E., Almeida, D.M., Rovine, M.J., Klein, L.C. (2014). Daily Stressors and Adult Day Service Use by Family Caregivers: Effects on Depressive Symptoms, Positive Mood, and Dehydroepiandrosterone-Sulfate. *Am J Geriatr Psychiatry*. (article in press)

Added in 2018

1. Easom, L., Cotter, E., and Ramos, A. (2018). Comparison of African American and Caucasian caregiver self-efficacy. *J of Gerontological Nursing*, 44 (3): 16-20.
2. Gresham, M., Heffernan, M., & Brodaty, H. (2018). The Going to Stay at Home program: Combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, 1-10.
3. Keisha I., Allen, R.S., Liu, Y., Parmelee, P.A. and Zarit, S.H. (2017). Immediate and lagged effects of daily stress and affect on caregivers' daily pain experience. *Gerontologist*, August 2017, (00): 1-10.
4. Klein, L.C., Kim, K., Almeida, D.M., Femia, E.E., Rovine, M.J., and Zarit, S.H. (2016). Anticipating an easier day: effects of adult day services on daily cortisol and stress. *Gerontologist*, 56 (2) 303-312.
5. Kumagai, N. (2017). Distinct impacts of high intensity caregiving on caregivers' mental health and continuation of caregiving. *Health Economics Review*, 7:15.
6. Leggett, A.N., Liu, Y., Klein, L.C. and Zarit, S.H. (2016). Sleep duration and the cortisol awakening response in dementia caregivers utilizing adult day services. *Health Psychology*, 35 (5): 465-473.
7. Liu, Y., Almeida, D.M., Rovine, M.J., and Zarit, S. (2018). Modeling cortisol daily rhythms of family caregivers of individuals with dementia: Daily stressors and adult day services use. *J Gerontol B Psychol Sci Soc Sci*, 73 (3): 457-467.
8. Lund, D.A., Utz, R.L., Caserta, M.S., Wright, S.D., Llanque, S. M., Lindfelt, C., Shon, H., Whitlach, C. J., Montoro-Rodriguez, J. (2014) Time for Living and Caring: An intervention to make respite more effective for caregivers. *Int'l J. Aging and Human Development*, 79 (2) 157-178.
9. Mensie, L.C. and Steffen, A.M. (2010). Depressive symptoms and use of home-based respite time in family caregivers. *Home Health Care Services Quarterly*, 29: 120-137.
10. Roberts, E. and Struckmeyer, K.M. (2018). The impact of respite programming on caregiver resilience in dementia care: a qualitative examination of family caregiver perspectives. *Journal of Health Care Organization, Provision and Financing*, 55: 1-11.
11. Tomita, N., Yoshimura, K., and Ikegami, N. (2010). Impact of home and community-based services on hospitalisation and institutionalization among individuals eligible for long-term care insurance in Japan. *BioMed Central Health Services Research*, 10: 345
12. Washington, T.R. and Tachman, J.A. (2017). Gerontological social work student-delivered respite: A community-university partnership pilot program. *Journal of Gerontological Social Work*, 60 (1): 48-67.

Added in 2020

1. Leggett, A.N., Meyer, O.L., Bugajski, B.C., Polenick, C. (2020). Accentuate the positive: the association between informal and formal supports and caregiving gains. *Journal of Applied Gerontology*, April 24; 1-9.
2. Parker, L.J., Gaugler, J.E., Samus, Q., and Gitlin, L.N. (2019). Adult day service use decreases likelihood of a missed physician's appointment among dementia caregivers. *J Am Geriatr Soc*, 67: 1467-1471.
3. Sakurai, S. and Kohno, Y. (2020). Effectiveness of respite care via short-stay services to support sleep in family caregivers. *Int. J. Environ. Res. Public Health*, 17: 2428-2438.
4. Vandepitte, S., Putman, K., Van Den Noortgate, N., Verhaeghe, S., Annemans, L. (2019). Effectiveness of an in-home respite care program to support informal dementia caregivers: A comparative study. *Int J Geriatr Psychiatry*, 34: 1534-1544.
5. Verbakel, E., Metzelthin, S.F., Kempen, G.I.J.M. (2018). Caregiving to older adults: Determinants of informal caregivers' subjective well-being and formal and informal support as alleviating conditions. *J Gerontol B Psychol Sci Soc*, 73 (6) 1099-1011.

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

1. Caldwell, J. and Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research*, 7 (4/5): 352-356.
2. Chou, Y.C., Tzou, P.Y., Pu, C.Y. Kroger, T. and Lee, W.P. (2008). Respite care as a community care service: Factors associated with the effects on family carers of adults with intellectual disability in Taiwan. *International Journal of Intellectual and Developmental Disability*, 33(1): 12-21.

IV. Studies of the outcomes of respite targeted to multi-age groups

Added in 2018

1. Ackerman, L. and Sheaffer, L. (2018). Effects of Respite care training on respite provider knowledge and confidence and outcomes for family caregivers receiving respite services. *Home Health Care Services Quarterly*, Feb 9: 1-20.
2. Institute for Research and Innovation, Shared Care Scotland (IRISS), Coalition of Carers in Scotland, and Minority Ethnic Carers of Older People Project (2012). *Rest assured? A study of unpaid carers' experiences of short breaks*. Dunfermline, Fife, Scotland: Shared Care Scotland.

Added in 2020

1. Shepherd, D., Goedeke, S., Landon, J., and Meads, J. (2020). The types and functions of social supports used by parents caring for a child with autism spectrum disorder. *J Autism Dev Disord*, Apr; 50(4):1337-1352.

V. Studies of Veterans' Administration Program of Comprehensive Assistance for Family Caregivers (PCAFC)

Added in 2018

1. Shepherd-Banigan, M., et al. (2018). Comprehensive support for family caregivers of post-9/11 Veterans Increases Veteran Utilization of Long-term Services and Supports: A Propensity Score analysis. *Journal of Health Care Organization, Provision, and Financing*, 55: 1-12.
2. Van Houtven, C.H., et al. (2017). Comprehensive support for family caregivers: Impact on Veteran health care utilization and costs. *Med Care Res Rev*, 1: 1-27.

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

1. Ingleton, C., Payne, S., Nolan, M., and Carey, I. (2003). Respite in palliative care: a review and discussion of the literature. *Palliat Med*, 17 (7): 567-75.
2. Jeon, Y., Brodaty, H., and Chesterson, J. (2005) Respite care for caregivers and people with severe mental illness: literature review. *Journal of Advanced Nursing*, 49 (3): 297-306.
3. Mason, A., Weatherly, H., Spilsbury, K, Golder, S., Arksey, H., Adamson, J., and Drummond, M. (2007). The effectiveness and cost-effectiveness of respite for caregivers of frail older people. *J Am Geriatr Soc*, 55(2): 290-9.
4. Pinqart, M. and Sorensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18: 4, 577-595.
5. Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., and Emerson, E. (2011). The Impacts of short break provision on families with a disabled child: an international literature review. *Health & Social Care in the Community*, 19 (4): 337-371.
6. Shaw, C., McNamara, R., Abrams, K., Cannings-John, R., Hood, K., Longo, M., Myles, S., O'Mahony, S., Roe, B., and Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment*, 13: 20.
7. Strunk, J.A. (2010). Respite care for families of special needs children: A systematic review. *Journal of Developmental & Physical Disabilities*, 22 (6): 615-630.

Added in 2018

1. Broady, T. and Aggar, C. (2017). Carer interventions: An overview of service effectiveness. *J of the Australasian Rehabilitation Nurses' Association*, 20 (2), 5-11.
2. Edelstein, H., Schippke, J., Sheffe, S., Kingsnorth, S. (2016). Children with medical complexity: a scoping review of interventions to support caregiver stress. *Child Care, Health and Development*, 43 (3): 323-333.
3. Fields, N.L., Anderson, K.A., and Dabelko-Schoeny, H. (2014). The effectiveness of adult day services for older adults: A review of the Literature from 2000 to 2011. *Journal of Applied Gerontology*, 33 (2): 130-163.

4. Knapp, M., Lemmi, V., and Romeo, R. (2013). Dementia care costs and outcomes: a systematic review. *Int J Geriatr Psychiatry*, 28: 551-561.
5. Lopez-Hartmann, M., Wens, J., Verhoeven, V., and Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers or community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care*, 12: 1-14.
6. Neville, C., Beattie, E., Fielding, E. and MacAndrew, M. (2015). Literature review: Use of respite by carers of people with dementia. *Health and Social Care in the Community*, 23 (1), 51-63.
7. Tretteteig, S., Vatne, S. and Rokstad, A.M.M. (2016). The influence of day care centers for people with dementia on family caregivers: An integrative review of the literature. *Aging & Mental Health*, 20(5): 450-462.
8. Vandepitte, S.V., Noortgate, N.V.D., Putman, K., Verhaeghe, S., Verdonck, C. and Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review. *Int J Geriatr Psychiatry*, 31: 1277-1288.
9. Whitmore, K.E. (2016). Respite care and stress among caregivers of children with autism spectrum disorder: an integrative review. *J Pediatr Nurs*, 31(6):630-652.

Added in 2020

1. Ellen, M.E., Demaio, P., Lange, A., and Wilson, M.G. (2017). Adult day center programs and their associated outcomes on clients, caregivers, and the health system: a scoping review. *The Gerontologist*, 57 (6): 85-94.
3. Maffioletti, V.L.R., Baptista, M.A.T., Santos, R.L., Rodrigues, V. M., Dourado, M.C.N. (2019). *Dement Neuropsychol*, Jul-Sep; 13(3): 268–283.
4. Walter, E., and Pinguart, M. (2019). How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. *The Gerontologist*, Advance Access publication September 17, 2019.

VII. Methodological Issues in Research on Respite and Caregiver Interventions

Added in 2018

1. Zarit, S.H. (2017). Past is prologue: How to advance caregiver interventions. *Aging & Mental Health*, 10: 1-5.
2. Zarit, S., Bangerter, L., Liu, U., and Rovine, M.J. (2017). Exploring the benefits of respite services to family caregivers: methodological issues and current findings. *Aging & Mental Health*, 21 (3): 224-231.

I. Studies of the outcomes of respite targeted to children

1. Aniol, K., Mullins, L.L., Page, M.C., Boyd, M.L., & Chaney, J.M. (2004). The relationship between respite care and child abuse potential in parents of children with developmental disabilities: A preliminary report. *Journal of Developmental and Physical Disabilities*, 16(3): 273-285.

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

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

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

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

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

2. Bernard-Brak, L. and Thomson, D. (2009). How is taking care of caregivers of children with disabilities related to academic achievement? *Child Youth Care Forum*, 38: 91-102.

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

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

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

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

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

3. Cole, S.A., Wehrmann, K.C. , Dewar, G. and Swinford, L. (2005). Crisis nurseries: Important services in a system of care for families and children. *Children and Youth Services Review*, 27 (9): 995-1010.

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

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

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

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

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

4. Cole, S.A. and Hernandez, P.M. (2008). Crisis nursery outcomes for caregivers served at multiple sites in Illinois. *Children and Youth Services Review*, 30: 452-465.

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

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

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

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

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

5. Cole, S.A. and Hernandez, P.M. (2011). Crisis nursery effects on child placement after foster care. *Children and Youth Services Review*, 33: 1445-1453.

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

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

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

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

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

6. Collins, M., Langer, S., Welch, V., Wells, E., Hatton, C., Robertson, J., Emerson, E. (2013). A Break from Caring for a Disabled Child: Parent Perceptions of the Uses and Benefits of Short Break Provision in England. *British Journal of Social Work*, 26(4): 271-83.

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

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

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

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

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

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

7. Cowen, P., Reed, D. (2002). Effects of respite care for children with developmental disabilities: evaluation of an intervention for at-risk families. *Public Health Nursing*; 19 (4): 272–283.

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

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

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

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

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

8. Davies, B., Steele, R., Collins, J., Cook, K., and Smith, S. (2004). The impact on families of respite care in a children's hospice program. *Journal of Palliative Care*, 20 (4): 277-286.

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

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

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

Study Limitations (as cited by authors): None cited

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

9. Harper, A., Dyches, T.T., Harper, J., Roper, S.O., and South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 43 (11): 2604-2616.

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

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

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

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

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

10. Mandell, D.S., Ming Xie, M.S., Morales, K.H., Lawer, L., McCarthy, M., and Marcus, S.C. (2012). The interplay of outpatient services and psychiatric hospitalization among Medicaid-enrolled children with autism spectrum disorders. *Arch Pediatr Adolesc Med*, 166 (1): 68-73

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

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

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

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

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

11. McConkey, R., Gent, C., and Scowcroft, E. (2013). Perceptions of effective support services to families with disabled children whose behavior is severely challenging: A multi-Informant study. *J Appl Res Intellect Disabil*, 26 (4): 271-83.

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

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

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

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

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

12. Meltzer, J. and Bennett Johnson, S. (2004). Summer camps for chronically ill children: a source of respite care for mothers. *Children's Healthcare, 33 (4): 317-331.*

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

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

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

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

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

13. Mullins, L.L., Aniol, K., Boyd, M. L., Page, M.C., and Chaney, J.M. (2004). The influence of respite care on psychological distress in parents of children with developmental disabilities: a longitudinal study. *Children's Services: Social Policy, Research, And Practice*, 5 (2): 123-138.

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

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

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

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

Authors' Discussion/Conclusions: "Taken together the results on parental outcomes suggest that brief inpatient respite care admission may well serve to diminish the more general distress that parents feel on a day to day basis and have positive benefits for the children as well." The authors recommend that future research address the limitations of their study design and allow for documenting the differential effectiveness of respite with specific subgroups of children and families. They also expressed the need for research to assess the effect of respite services on the likelihood of maltreatment or abandonment, and the impacts of respite on overutilization of other health care services and long-term out-of-home placements.

14. Olsen, R. and Maslin-Prothero, P. (2001). Dilemmas in the provision of own-home respite support for parents of young children with complex health care needs: evidence from an evaluation. *Journal of Advanced Nursing*, 34 (5): 603-610.

Study Aim/Purpose: To examine parent responses and effects of a nurse-led in-home respite support service for parents of young children with complex health care needs.

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

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

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

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

15. Owens-Kane, Sandra. (2007). Respite Care: Outcomes for Kinship and Non-Kinship Caregivers. *Journal of Health & Social Policy*, 22 (3/4): 85-99.

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

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

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

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

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

16. Pascuet E., Cowin L., Vaillancourt R., Splinter W., Vadeboncoeur C., Dumond L.G., Ni A., and Rattray M. (2010). A comparative cost-minimization analysis of providing pediatric palliative respite care before and after the opening of services at a pediatric hospice. *Healthcare Management Forum*, 23 (2): 63-66.

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

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

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

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

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

Added in 2018

1. Crampton, D. and Yoon, S. (2016). Crisis nursery services and foster care prevention: An exploratory study. *Children and Youth Services Review*, 61: 311-316.

Study Aim/Purpose: This study explored the relationship between receipt of short-term crisis nursery services, including case management and parenting education, and children's subsequent foster care placement.

Summary of Methods: This was a cross-sectional study examining administrative data on 186 families and their 322 children who received crisis nursery services in Cleveland, Ohio, between 2006 and 2009. The crisis nursery program administrative data file provided information on parent and child demographics, referral sources, and reason, type of crisis nursery services received, dates of inquiry and discharge. The two key independent variables were receipt of case management and parenting education services as recommended by the crisis nursery. Generalized estimating equations analysis was used to assess the relationship between receipt of recommended crisis nursery services and subsequent foster care placement. Information on foster care placement before and/or after using crisis nursery respite was obtained by matching crisis nursery data to the county's Childhood Integrated Longitudinal Data System which integrates birth records with records from many health and human services agencies, including the Department of Children and Family Services, which administers foster care.

Summary of Results: Children whose families received case management had 65 percent lower odds of having subsequent foster care placement than children in families who were recommended to, but did not receive case management. Similarly, those children whose families participated in parenting education had 65 percent lower odds of subsequent foster care placement than children in families who were recommended to, but did not participate. Other significant predictors of subsequent foster care identified included previous foster care placement during the 12 months prior to receiving crisis nursery respite and the child's race. Caucasian children had 8-9 times higher odds of subsequent foster care placement than biracial children and African American children had 3 times higher odds than biracial children.

Study Limitations (as cited by authors): The authors note several limitations of their research design noting its cross-sectional nature and dependence on data in the administrative dataset.

Authors' Discussion/Conclusions: The authors suggest that crisis nursery services delivered with case management and parenting education may be an effective and cost-effective intervention to reduce children's foster care placement and recommend partnerships between crisis nurseries and public child welfare agencies as a foster care prevention strategy. They also note that children who have had foster care experience prior to receiving crisis nursery services warrant special attention since they are at heightened risk of repeated placement. The authors suggest future research should link crisis nursery administrative data with a broader array of programs serving vulnerable families. They also suggest qualitative research to better understand the factors that might account for the racial differences found in this study.

2. Dyches, T.T., Christensen, R., Harper, J.M., Mandleco, B., and Roper, S.O. (2016). Respite care for single mothers of children with autism spectrum disorders. *J Autism Dev Disord*, 46: 812-824.

Study Aim/Purpose: This study sought to measure how use of respite care was associated with depression levels among single mothers of children with autism spectrum disorders (ASD).

Summary of Methods: This was a cross-sectional study with a sample of 122 single mothers who had at least one child with ASD. Mothers were recruited to complete a 15-20 minute survey through various channels, including electronic social media, newsletters, and organizations related to ASD. The survey collected demographic information and included items from four self-report behavioral tools: (1) the 20-item Center for Epidemiological Studies Depression Scale (CES-d); (2) the 20-item Caregiver Burden Instrument; (3) the Hassles and Uplifts Scale which asks respondents to indicate how much of a daily hassle or uplift they experience from 53 items; and (4) questions about the amount of respite care they receive, the providers of respite care, satisfaction with care, and how they spent their time while others were caring for their child(ren). Structural equation modeling was used to analyze the association between respite care receipt and depression as the dependent variable. Analysis also measured the mediating effects of stress and uplifts on depression.

Summary of Results: The authors found that about 60 percent of respondents accessed some form of respite care for an average of 7 hours per week; satisfaction was high for respite received; and the majority either worked or ran errands during the respite time. Mothers who reported more daily uplifts on average reported fewer symptoms of depression. The intensity of daily hassles and caregiver burden were independently significantly positively correlated with reported depression symptoms. However, the authors did not find an association between amount of respite care received and depressive symptoms or stress. They did find that uplifts were a mediating variable between respite care and depression.

Study Limitations (as cited by authors): Authors noted that the study's sample size and cross sectional design limited its ability to analyze correlational relationships and the direction of effects between variables. They also noted that the findings' generalizability is limited by the demographics of the respondents who were mostly non-Hispanic White, fairly well educated, had internet access, and lived in the Western region of the U.S.

Authors' Discussion/Conclusions: The authors suggested that the lack of association between respite care receipt and mothers' stress or depression may be explained by other variables not measured in this study, such as financial and job stress or by the fact that single mothers are saturated with stress and thus not as impacted by respite care as those caregivers whose conditions are less intense. They recommended research to determine how much more respite is needed to make a positive impact on depression and stress of single mothers of children with ASD and recommended applied research and public policies to improve access to respite care for single mothers of children with ASD.

3. **Madden, E.E., Chanmugam, A., McRoy, R.G., Kaufman, L., Ayers-Lopez, S., Boo, M., and Ledesma, K. J. (2016). The impact of formal and informal respite care on foster, adoptive, and kinship parents caring for children involved in the child welfare system. *Child Adolesc Soc Work J*, 33: 523-534.**

Study Aim/Purpose: This study explored the utilization of formal and informal respite services by foster, adoptive and kinship parents, as well as the association between each of these kinds of respite on family experiences, ability to care for their children, and stress levels.

Summary of Methods: Using a cross sectional study design, the authors conducted a survey that included a final sample of 160 foster, adoptive and kinship parents who had participated in parent support groups. The 42-item survey collected information on parent demographics and the type of respite the parents had received, and measured parents' perception of the outcomes of respite (ability to care for their children, reduced stress, family stability, and family cohesion) as well as their reasons for using respite. The respite was categorized as either formal, informal, or a mixture of the two. "Formal" respite was defined to include financial assistance by an external entity to pay for in-home caretakers, group activities for children and youth hosted by parent support groups, or services provided by a private trained provider, respite care agency, day care or institution. "Informal" respite was defined to include paid or unpaid child care provided by friends, family, neighbors, or other caretakers selected by the respondent who were not reimbursed from an external entity.

Summary of Results: The large majority of respondents reported positive outcomes of receiving respite, regardless of type. This was true on all the outcome/ family experience measures. Parents who used a combination of formal and informal respite reported positive experiences related to respite more frequently than the parents who received just formal or just informal respite, with a particularly stronger association with family stability. Additionally, parents who had used formal respite (either alone or mixed with informal respite) reported greater stress reduction than those who had only used informal respite.

Study Limitations (as cited by authors): Study authors noted several limitations in their research. Particularly they suggested that because the sample was recruited from support group participants, the findings may not be generalizable to a broader population of foster, adoptive and kinship parents. The lack of data on the children was also noted as a limitation.

Authors' Discussion/Conclusions: The authors suggest several practical implications of their findings. First, they recommend that families should use a mix of informal and informal respite care to allow them to maximize opportunities for taking care of themselves and their families' needs. Second, they recommend that access to formal respite care should be increased for this population because of its beneficial effect on reducing stress levels and enhancing family stability. They also stress that further research is needed to examine how outcomes for families vary based on the type of respite services accessed as well as the need for more research to examine the benefits of respite services for children.

4. Remedios, C., Willenberg, L., Zordan, R., Murphy, A., Hessel, G. and Philip, J. (2015). A pre-test and post-test study of the physical and psychological effects of out-of-home respite care on caregivers of children with life-threatening conditions. *Palliative Medicine*, 29 (3): 223-230.

Study Aim/Purpose: This study sought to measure the association between planned, overnight out-of-home hospice respite stays on parental caregivers fatigue level, psychological adjustment, quality of life, and relationship satisfaction.

Summary of Methods: This study surveyed parental caregivers whose children spent an average of four days in Very Special Kids (VSK), out-of-home overnight hospice setting for children in Melbourne, Australia. Data were collected by mail survey two weeks prior to admission and then approximately one week after discharge. 58 caregivers completed valid baseline surveys and 39 completed valid post-respite surveys. The pre-respite survey contained sociodemographic questions, standardized measures on quality of life (using the SF-12 Health Survey), psychological adjustment (using the General Health Questionnaire), fatigue (using the Chalder Fatigue Scale), relationship quality (Using the Quality of Marriage Index), and social support (using the Multidimensional Scale of Perceived Social Support), and open-ended questions regarding perceptions of caring, major life events, financial stability and reasons for requiring respite. The post-respite survey contained the same close-ended questions and open-ended questions about perceptions of respite and other palliative care services of VSK. Descriptive statistics were used to describe the study population, paired t-tests were used to examine pre/post differences on the key study outcomes, and the qualitative responses were analyzed using content analysis.

Summary of Results: At baseline, on average, scores on the general health scale showed clinical levels of distress; scores on the fatigue scale showed moderate levels of fatigue; and caregivers reported having a good quality of relationship with their partner. Qualitatively, aside from care provision, their own physical and mental health problems were the most commonly cited major life issues for caregivers. Caregivers' comments also demonstrated that financial pressures were significant stressors in their lives. Analysis of pre and post-respite responses found significant improvements in caregivers' reported psychological adjustment, fatigue and mental health quality of life soon after respite use. No significant improvements were found in caregivers' reported physical health, quality of life, or partner relationships (though the latter had little room for improvement based on baseline reports).

Study Limitations (as cited by authors): The authors cite the small sample size, low response rate post-respite and lack of a control arm as the study's key limitations.

Authors' Discussion/Conclusions: The authors point to their results to support overnight respite care as an integral and accessible part of support for families of children with life threatening conditions. They also highlight the need for future research to identify additional pediatric palliative care interventions that can reduce the high levels of stress and burden among this population of caregivers.

Added in 2020

1. Eddy, J.M., Shortt, J.W., Martinez, C.R., Holmes, A., Wheeler, A., Gau, J., Seeley, J. Grossman, J. (2020). Outcomes from a randomized controlled trial of the Relief Nursery program. *Prevention Science*, 21: 36-46. <https://doi.org/10.1007/s11121-019-00992-9>

Study Aim/Purpose: This study examined the impacts of the Relief Nursery program, established in the mid-1970s in the Eugene-Springfield community of Oregon. The program is designed to provide a comprehensive array of family support services to low-income families at risk of child abuse and neglect, including home visiting, parent education and a therapeutic early childhood education classroom, respite services, and additional services tailored to each family's needs.

Summary of Methods: Families with children between the ages of 18 months and four years who contacted the program for the first time were randomly assigned to the “full program” condition or “respite care only” condition. Respite care provided to the two groups was of equal quality but provided in a different physical location. A total of 180 primary caregivers (95% women) and 180 children initially participated in the study, which lasted two years with a very high retention rate. Eighty-three percent of the participants were White, 15 percent were multiracial, and in terms of ethnicity 42% were Latinx. Thirty-six percent of caregivers had been homeless, 28 percent had been diagnosed with a mental health condition, 23 percent had serious drug or alcohol problems, and 25 percent had been arrested.

Interviews with caregivers were conducted at baseline and every 6 months for two years to measure the following outcomes: family strengths and resources (assessed using the Family Functioning Style Scale); availability of social supports (measured using the Social Support Questionnaire); potential for child abuse (measured using the Child Abuse Potential Inventory); parenting quality (assessed using the Alabama Parenting Questionnaire; caregivers' parenting self-efficacy (assessed using a total score from the Being a Parent question items); parental depression (measured using the Center for Epidemiologic Studies Depression Scale); family stress (measured using the Parental Stress Index); and child behavior problems (assessed using the 113 item Child Behavior Checklist-Parent). Beginning with the first follow-up interview, families were also asked about their satisfaction with the services received. Receipt of respite care, requests for referrals, and characteristics of the components of the full program attended were also documented.

Summary of Results: At the six-month interview (wave 2), after controlling for baseline differences between the two groups, no significant differences in outcome effects were found. However, at the two-year (wave 4) interview and the end of the 2-year study period (wave 5) there were significantly higher levels of social support reported by caregivers in the Full Program than by caregivers assigned to the Respite Care only condition. Outcome differences were not found on any measures of family functioning or child behaviors. While participants in both study groups expressed satisfaction with the services received, those in the “full program” expressed higher levels of program helpfulness and satisfaction.

Limitations of Study: The authors noted several limitations in the study design, including the small sample size and the use of only one tool for measurement of outcomes. They also indicated that the study results were impacted by unexpected decreases in program funding, which had negative effects

on program staffing and their ability to refer to other services, and thus also potentially limited participants' participation over time in the program's core components. They also explained that, while enrollment in the Respite Nursery program is based on self-referral, the resulting selection bias may result in different population characteristics among the study population than the larger population of families who are at risk for child abuse and neglect, and thus the results would not be generalizable.

Authors' Discussion/Conclusions: The authors conclude that their findings of the program's limited impact may have been in part due to the relatively low levels of program staffing and its effect on their ability to engage families and thus to ensure provision of all of the services. They recommend that, in order to assure adequate dosage of the intervention to study participants, the protocols should incorporate a variety of purposeful strategies to so that all components reach over 90 percent of families for a significant period of time. They also suggest that it may be more useful to evaluate program impacts on a homogeneous group of families, e.g., those with similar parent, child, and family needs, and who are identified as "high risk" specifically for child abuse and neglect.

2. Norton, M., Dyches, T.T., Harper, J.M., Roper, S.O., & Caldarella, P. (2016). Respite care, stress, uplifts, and marital quality in parents of children with Down syndrome. *Journal of Autism and Developmental Disorders*. doi: 10.1007/s10803-016-2902-6

Study Aim/Purpose: This study's primary purpose was to examine the relationship between respite care use and wives' and husbands' perception of their marital quality. It also sought to assess wife and husband stress and uplifts (defined as positive experiences) as possible mediating variables of the relationship between respite care and perceived marital quality.

Summary of Methods: English speaking married couples from the U.S. who had a child with Down syndrome were recruited to participate in a national survey through local and regional organizations and Facebook postings. The final study sample included 224 couples (husband and wife) who completed the survey independently. Information was collected on respondent demographics, use of respite care (broadly defined), perceptions of marital quality, and the frequency and intensity of daily stressors and/or uplifts. Marital quality was assessed using indicators from the Revised Dyadic Adjustment Scale, and the avoidance attachment subscale and anxious attachment subscales of the Revised Experiences in Close Relationships Questionnaire. Frequency and intensity of stressors and uplifts were assessed using the Hassles and Uplifts Scale with respondents rating how much each of 53 items are "a daily hassle" and how much each of the items are "a daily uplift" for them

Data were analyzed with structural equation modeling. An Actor-Partner Independence Model was used to estimate effects of the amount of respite care on husband and wife relationship quality. The influence of each partner's stressors and uplifts on her or his spouse was calculated. The indirect paths of daily uplifts and stressors mediating between respite care and marital quality were also calculated.

Summary of Results: Study respondents who used respite care mostly received respite provided by grandparents, with very little provided by community agencies. Results did not find a statistically significant positive relationship between amount of respite care and marital relationship quality or between respite care and husbands' and wives' daily uplifts. At the same time, respite care was negatively related to both wife and husband stress. The study found that for both wives and husbands daily stress significantly mediated the path from hours of respite used to that spouse's perception of marital quality. At the same time, daily uplifts were positively related with marital quality for both spouses who reported them. Wife uplifts were also positively correlated with husband perceptions of marital quality and the more perceived uplifts the wife reported experiencing the better marital quality both spouses reported.

Limitations of Study: The authors noted several limitations in the study design, including the fact that most study participants were Caucasian and mainly recruited from local and regional organizations that may provide ongoing support for these families that is not available to many minority populations. They note that self-reporting of what was considered respite care may have also resulted in certain biases. Third, they acknowledge that as a cross sectional study design, inferences cannot be drawn about the causation among the variables that are associated. Because participants were asked to consider each of

the 53 items for the daily Hassles and Uplifts Scale as both a stressor and an uplift, the authors acknowledge that there could be shared variance between the measures.

Additionally, the authors suggest that although the study did not find a correlation between respite care and uplifts, this may be due to characteristics and behaviors of the study population. First, the uplift scores of the study population were already fairly high for both husbands and wives; thus, the number of hours of respite care may not have been sufficient to further increase their scores. Second, the activities the parents performed while their child was receiving respite (e.g. running errand or doing chores) may not have resulted in uplifts.

Authors' Discussion/Conclusions: The authors conclude with several policy recommendations supported by their findings including expansion of funding for formal respite care and tax policies that recognize the special expenses and/or loss of income and Social Security benefits for those providing in home care to family members with chronic conditions or disabilities. They also recommend that consideration of respite care services be an integral part of children's Individual Family Service Plan (IFSP) or Individualized Education Program (IEP) through the schools. They stress that schools may be an important intervention point for community organizations to link trained respite care providers to families in need of respite. Because respite care helps reduce stress, and lower levels of stress increase marital quality, the authors recommend that programming be provided to provide respite care to married families to assist families in reduction of daily stress levels. The authors also highlight the importance of including the perspective of fathers in research on the families raising children with Down syndrome and their needs.

They suggest several implications for future research including identification of the factors that affect respite care access, understanding what activities parents engage in that maximize the benefit of receiving respite care, and studies that specifically identify what family characteristics or resources predict marital quality in families raising children with Down syndrome, which was very high in this study population.

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

1. Carretero, S., Garces, J., and Rodenas, F. (2007). Evaluation of the Home Help Service and its impact on the informal caregiver's burden of dependent elders. *Int J Geriatr Psychiatr*, 22 (8): 738-49.

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

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

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

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

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

2. Empeño, J., Raming, N.T., Irwin, S.A., Nelesen, R.A. and Lloyd, L.S. (2011.) The hospice caregiver support project: Providing support to reduce caregiver stress. *Journal of Palliative Medicine*, 14 (5): 593–597.

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

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

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

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

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

3. Fernia, E.E., Zarit, S.H., Stephens, M.A., and Greene, R. (2007). Impact of adult day services on behavioral and psychological symptoms of dementia. *The Gerontologist*, 47 (6): 775-788.

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

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

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

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

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

4. Gaugler, J. E., Jarrott, S. E., Zarit, S.H., Stephens, M-A.P. Townsend, A., and Greene, R. (2003). Adult day service use and reductions in caregiving hours: Effects on stress and psychological well-being for dementia caregivers. *International Journal of Geriatric Psychiatry*, 18 (1), 55–62.

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

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

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

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

Authors' Discussion/Conclusions: The authors suggest that the following as explanation for the study's positive findings of associations between ADS use and reported "role overload." By relinquishing care

demands for several hours a week, adult day service users could have had more time to complete other necessary demands efficiently when compared to caregivers whose relatives remained at home, thus leading to decreased feelings of exhaustion. Alternatively, some adult day programs may have provided services that helped reduce more severe disorientation and/or repetitious questioning on the part of clients. By addressing the memory problems of clients, adult day services may have offered caregivers the relief necessary to reduce feelings of exhaustion and fatigue.

5. Gitlin, L.N., Reeve, K., Dennis, M.P., Mathieu, E., and Hauck, W.W. (2006). Enhancing quality of life of families who use adult day services: short- and long-term effects of the Adult Day Services Plus Program. *The Gerontologist*, 46 (5): 630-639.

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

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

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

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

Authors' Discussion/Conclusions: "The study clearly demonstrates the potential benefits of targeting both the older person using ADS as well as the family caregiver in assessment and treatment." This approach "may also serve as a model for integrating caregiver assessment and treatment into other long term care service programs that traditionally target only the impaired adult." Furthermore, "although an important objective of ADS is to help families delay nursing home placement, this study suggests that

without systematically targeting the concerns of family caregivers, this objective may not be fully achieved.” The authors suggest that further research is needed to substantiate the findings of this study to other centers, examine the components of the intervention to determine which components contribute to improved caregiver outcomes, and to conduct analyses of costs and cost savings.

6. Hancock, P.J., Jarvis, J.A., and L'Veena, T. (2007). Older Carers in Ageing Societies: An Evaluation of a Respite Care Program for Older Carers in Western Australia. *Home Health Care Services Quarterly*, 26 (2): 59-84.

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

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

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

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

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

7. Lee, D., Morgan, K., and Lindsay, J. (2007). Effect of institutional respite care on the sleep of people with dementia and their primary caregivers. *J Am Geriatr Soc*, 55 (2): 252-8.

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

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

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

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

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

8. LaVela, S.L., Johnson, B.W., Miskevics, S. and Weaver, F.M. (2012). Impact of a multicomponent support services program on informal caregivers of adults aging with disabilities. *Journal of Gerontological Social Work*, 55: 160-174.

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

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

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

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

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

9. Lund, D.A., Utz, R., Caserta, M.S., and Wright, S.D. (2009). Examining What Caregivers Do During Respite Time to Make Respite More Effective. *Journal of Applied Gerontology*, 28 (1): 109-131.

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

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

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

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

Authors' Discussion/Conclusions: The authors recommend that, based on their study findings, more attention should be paid to helping caregivers carry out satisfying activities during available respite time. They recommend that providers and researchers help respite users in the following ways: "(a) assessing their situations, resources, and needs; (b) determining what types and amount of respite activities might be most beneficial to them given their preferences and areas in which their lives are being most negatively affecting by caregiving; c) setting specific goals for how to use their upcoming respite time;

(d) developing a plan to make their goals achievable...; (e) evaluating the effectiveness of the outcomes of respite; and (f) making goal setting and evaluation ongoing activities...” In terms of future research, the authors suggest “that studies place an emphasis on theoretically based interventions and longitudinal designs that are tailored to the individual needs of each caregiver...Also needed are studies that assess diverse forms of formal and informal respite services and include more diverse populations and provide appropriate culturally sensitivity to the ethnic and racial differences among caregivers.”

**10. Mavall, L. and Thorslund, M. (2007). Does day care also provide care for the caregiver?
Arch Gerontol Geriatr, 45 (2): 137-50.**

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

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

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

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

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

11. Neville, C.C. and Byrne, G.J. (2006). The impact of residential respite care on the behavior of older people. *Int Psychogeriatr*; 18 (1): 163-70.

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

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

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

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

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

12. Perry, J. and Bontinen, K. (2001). Evaluation of a weekend respite program for persons with Alzheimer Disease. *Can J Nurs Res*, 33: 81–95

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

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

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

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

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

13. Schmitt, E.M., Sands, L.P., Weiss, S., Dowling, G., and Covinsky, K. (2010). Adult Day Health Center Participation and Health-Related Quality of Life. *The Gerontologist*, 50(4): 531-540.

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

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

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

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

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

14. Smeets, S.M., vanHeugten, C.M., Geboers, J.F., Visser-Meily, J.M., Schepers, V. P. (2012). Respite care after acquired brain injury: The well-being of caregivers and patients. *Arch Phys Med Rehabil*, 93: 834-41.

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

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

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

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

Authors' Discussion/Conclusions: The authors conclude that "the results of this study suggest that for better caregiver functioning, interventions should target mastery and coping skills of both caregivers and patients." "In the current study, patients were already in the chronic phase of their injury, and a more constructive approach in this group should stress self-management of the consequences of brain injury and continuous support for both caregivers and patients" with ABI after the acute phase and discharge from the hospital or rehabilitation center. With regard to future research, the authors

recommend research to “provide knowledge about the contribution of each component and type of (respite) care to the well-being of caregivers and patients.”

15. Tompkins, S.A. and Bell, P.A. (2009). Examination of a psychoeducational intervention and a respite grant in relieving psychosocial stressors associated with being an Alzheimer's caregiver. *Journal of Gerontological Social Work*, 52: 89-104.

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

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

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

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

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

16. Utz, R.L., Lund, D.A., Caserta, M.S., and Wright, S.D. (2012). The Benefits of Respite Time-Use: A Comparison of Employed and Nonemployed Caregivers. *Journal of Applied Gerontology*, 31: 438-461.

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

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

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

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

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

17. Warren, S., Kerr, J.R., Smith, D., and Schalm, C. (2003). The impact of adult day programs on family caregivers of elderly relatives. *J Community Health Nurs*; 20(4): 209-21.

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

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

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

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

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

18. Whitlach, C.J. and Feinberg, L.F. (2006). Family and Friends as Respite Providers, *Journal of Aging & Social Policy*, 18 (3-4): 127-139.

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

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

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

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

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

**19. Zarit, S.H., Kim, K., Femia, E.E., Almedia, D.M., Savla, J. and Molenaar, P.C.M. (2011).
Effects of Adult Day Care on Daily Stress of Caregivers: A Within-Person Approach.
J Gerontol B Psychol Sci Soc Sci, 66 (5): 538–546.**

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

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

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

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

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

20. Zarit, S.H., Kim, K., Femia, E.E., Almedia, D.M., and Klein, L.C. (2014). The effects of adult day care services on family caregivers' daily stress, affect, and health: outcomes from the Daily Stress and Health (DaSH) Study. *The Gerontologist*, Vol 54, Issue 4, pages 570-579.

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

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

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

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

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

21. Zarit, S.H., Whetzel, C.A., Kim, K., Femia, E.E., Almedia, D.M., Rovine, M.J., Klein, L.C. (2014). Daily Stressors and Adult Day Service Use by Family Caregivers: Effects on Depressive Symptoms, Positive Mood, and Dehydroepiandrosterone-Sulfate. *Am J Geriatr Psychiatr.* 22(12):1592-602.

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

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

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

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

Authors' Discussion/Conclusions: The authors note that this is "one of the few studies demonstrating an effect of a caregiving intervention on physiologic indicators of stress." While recognizing that effect size was small in this study, the authors suggest broadening the focus of evaluations of caregiver interventions "to include their impact on relevant biologic risk factors associated with chronic stress and disease."

Added in 2018

1. Easom, L., Cotter, E., and Ramos, A. (2018). Comparison of African American and Caucasian caregiver self-efficacy. *J of Gerontological Nursing*, 44 (3): 16-20.

Study Aim/Purpose: This study examined the self-efficacy impacts of an intervention targeted to caregivers of individuals with Alzheimer's diseases, with a specific focus on differences in effects on African American versus Caucasian caregivers.

Summary of Methods: This study evaluated the Resources for Enhancing Alzheimer's Caregiver Health (REACH II) intervention, using a pre/post quasi experimental design with a sample of 123 caregivers (54 percent African Americans and 40 percent Caucasian) who lived with or were responsible for daily meal preparation for an individual with Alzheimer's disease or related dementia. To be eligible, caregivers of individuals with Alzheimer's or dementia also had to verbally express that their care recipient had memory problems, provide at least 4 hours of care per day, and rate themselves as having stress at a level of 5 or greater on a scale of 1 to 10. Study participants completed nine in-home sessions and three caregiving coach telephone conversations of 12 REACH II sessions over six months and completed a survey at the first and last home visit. Statistical analysis measured the effects of the intervention on caregivers' self-efficacy, measured using the 15-item checklist known as the *Revised Scale for Caregiving Self-Efficacy*. Subscales for self-efficacy included (1) obtaining respite, (2) response to disruptive behaviors, and (3) controlling their upsetting thoughts about caregiving.

Summary of Results: Statistical analyses of racial differences found that both African-American and Caucasian caregivers showed significant and comparable magnitudes of improvement in overall self-efficacy and in all the subscales, which contradicted the authors initial hypothesis. Another interesting finding was that African American caregivers both started and finished with higher levels of self-efficacy than Caucasian caregivers and this was consistent for all subscales measured.

Study Limitations (as cited by authors): The authors noted that the study sample size and limited geographic area may limit the generalizability of findings. Additionally, they acknowledged that because the caregiver race groups were not matched for severity of the care recipient's dementia severity this may have caused bias.

Authors' Discussion/Conclusions: Recognizing that African American individuals have not in the past been adequately included in health care research samples, the authors recommend follow-up research to examine whether their results represent an anomaly unique to the current sample or more generalizable racial differences that can help guide culturally responsive programming for caregivers. They recommend that future studies include more racially diverse populations and be designed to determine which individual or combined components of caregiver support programming like REACH II are effective in encouraging caregivers to seek respite.

2. Gresham M., Heffernan, M., and Brodaty, H. (2018). The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, 1-10.

Study Aim/Purpose: This Australian study examined the effects of a short term residential caregiver education and respite program called the Going to Stay at Home (G TSAH) program. G TSAH was provided to caregiver/care recipient dyads, with a care recipient who had dementia who volunteered to stay in a residential care home for five days. During their stay, caregivers received 14 sessions focusing on psychological support for them, education and information about dementia and its progression, coping and home care skills, problem solving and behavioral management techniques, developing support systems, and planning for the future. The program component for persons with dementia consisted of activities that focused on sensory and cognitive stimulation, physical activity, reminiscence, environmental orientation, creativity, social interaction, and relaxation.

Summary of Methods: There were 85 caregiver and care recipient dyads who participated in this study. The caregivers completed validated questions from surveys and self-report questionnaires at baseline, and at 6 and 12 months post-participation. Caregiver outcomes measured included: anxiety and depression, burden, quality of life, caregiver health status, the number of caregiver needs met, and resource utilization. For the persons with dementia, the instruments measured changes in dementia behavioral symptoms and quality of life and function. The authors also compared the rate of 12-month permanent admission to a residential aged care home among G TSAH participants compared to a group of people with dementia who received residential care but did not receive the intervention. The difference in outcome measures before and after the intervention were examined using a one-way repeated ANOVA. Logistic regression was used to compare rates of residential care admissions between program participations and the comparison group.

Summary of Results: Study analysis results found no significant changes in caregiver distress, quality of life, burden, physical or mental health over time, despite decreasing function in their care recipients over the follow-up period. Caregivers reported an increase in the number of their needs being met relating to information, practical tasks, communication and managing behavior. Finally, and most remarkable, the percent of G TSAH participants who had entered permanent residential care within 12 months was much lower than the comparison group (17.6% compared to 52.9%).

Study Limitations (as cited by authors): The authors note several methodological limitations to this study. Foremost, they acknowledge that the study was a single arm prospective evaluation comparing caregiver and care recipient outcomes pre and post-intervention, without a control. Impact on residential placement was calculated using a comparison group, but not a control group. As a result, differences in recruitment procedures and characteristics of persons with dementia may have independently influenced the rates of permanent placement and the study sample who volunteered may not be representative of caregivers in the general population. A further limitation is that the authors were unable to conduct a cost benefit analysis based on savings achieved by reducing the rate of residential care admissions.

Authors' Discussion/Conclusions: The authors conclude that the study results demonstrate that G TSAH provides a model to help keep people with dementia living at home and to assist families to cope and it may have potential for achieving similar results for people living with other chronic diseases.

3. Keisha I., Allen, R.S., Liu, Y., Parmelee, P.A. and Zarit, S.H. (2017). Immediate and Lagged Effects of Daily Stress and Affect on Caregivers' Daily Pain Experience. *Gerontologist*, August 2017, (00): 1-10.

Study Aim/Purpose: The authors examined the immediate and lagged daily pain outcomes associated with daily levels of stress and adult day service (ADS) use among family caregivers of persons with dementia.

Summary of Methods: This longitudinal study involved daily telephone interviews with 173 family caregivers of persons with dementia who live in the same household and indicated that their primary responsibility is helping the individual with daily tasks, and whose care recipient attended ADS more than 2 days per week. Participants were initially interviewed in person to collect sociodemographic and baseline data (e.g. duration of care, ADL impairment of the individual with dementia, caregiver over-the-counter medication use, and reports of bodily pain frequency and interference). Subsequent daily telephone interviews assessed the following measures over eight consecutive days: (1) daily bodily pain; (2) use or nonuse of ADS; (3) daily positive and negative affect; (4) care related subjective stress; and, (5) non-care related subjective stress. Multilevel models were used to examine the relationship between daily stress and pain and interaction effects of stressors and caregiver affect within the context of ADS use.

Summary of Results: The authors found a significant association between care-related subjective stress and daily bodily reported bodily pain for the same day. Although ADS use alone was not associated with bodily pain, bodily pain was higher on ADS days when noncare-related stress was higher. Lagged effects revealed a significant interaction between use of ADS one day and the next day's positive affect and bodily pain. That is, caregivers who reported higher positive affect one day after ADS use also reported lower pain that next day.

Study Limitations (as cited by authors): Authors suggested several limitations of their study including potential selection bias since caregiver enrollment was voluntary, their use of only a single item as a measure of pain, and the fact that they did not examine the effects of positive perceptions of caregiving on caregiver outcomes. While their findings showed decrease in pain associated with prior day ADS use and positive affect, they noted that the findings could not inform what a clinically meaningful decrease in pain would be.

Authors' Discussion/Conclusions: The authors recommend further research to examine the combined effects of ADS use, noncare-related stress and positive affect. Additionally, they suggest that the cause of the reported physical pain will also be an important consideration for future research. This research, they explain, is important to identify the best kinds of interventions to reduce pain and associated stressors among informal caregivers, such as modules for caregivers regarding physical activity and active coping strategies such as mindfulness for pain management.

4. Klein, L.C., Kim, K., Almeida, D.M., Femia, E.E., Rovine, M.J., and Zarit, S.H. (2016). Anticipating an Easier Day: Effects of Adult Day Services on Daily Cortisol and Stress. *Gerontologist*, 56 (2) 303-312.

Study Aim/Purpose: This study investigates whether and how use of Adult Day Services (ADS) is associated with improved regulation of cortisol for caregivers.

Summary of Methods: The study followed 158 family caregivers who lived with individuals with dementia who were attending ADS at least two days a week. After an initial in-person interview to collect background information, data was collected for eight consecutive days using a Daily Record of Behavior. Participants were called each evening to assess daily stress experiences and positive experiences, confirm ADS use or nonuse for that day, and daily wake-up time. Five daily saliva samples were analyzed to calculate: (1) cortisol awakening response (CAR), defined as the extent of change in cortisol levels from awakening to 30 minutes after awakening; and (2) total daily cortisol output, measured as cortisol area under the curve with respect to ground (AUC-G). To determine the between group effects of ADS use and non-ADS use days, participants were divided up into four quartiles (high, medium-high, medium and low) based on their cortisol results on non-ADS days.

Summary of Results: The study found that caregivers had significantly fewer care-related stressors, more positive experiences, but also more noncare-related stressors on days of ADS use compared with days when they provided most or all of the care. Regarding effects of ADS on cortisol, ADS use was shown to have a positive effect on CAR. However, this effect varied based on caregivers' level of CAR on non-ADS use days. Specifically, caregivers with a burned-out or flattened CAR and associated low AUC-G (both biomarkers associated with exhaustion and perceived fatigue) on non-ADS days displayed a more normative CAR and AUC-G response on ADS days. Restored cortisol regulation was also observed on ADS days among the high quartile group (i.e., caregivers with the highest CAR and AUC-G levels) on non-ADS days. No other covariants analyzed had significant effects on caregivers' CAR, though total number of ADS days, caregiver's age, and daily wake-up time had associations with their AUC-G level.

Study Limitations (as cited by authors): The authors explain that there is likely selection bias in the study population given the intensive nature of the data collection. Additionally, although cortisol has been found to raise susceptibility to health problems, the authors point out that there are no clinical norms for risk.

Authors' Discussion/Conclusions: The authors conclude that ADS use provides partial relief from primary stressors of behavior problems as shown by the biomarker of cortisol level patterns. Future studies research is recommended to assess associations between daily stressor exposure and more than one kind of biomarker as well as the association between daily stress biomarkers and long-term health and well-being. To fully understand the health effects of respite care it is recommended that future research test the effects of daily ADS use and total ADS use across a period of time.

5. Kumagai, N. (2017). Distinct impacts of high intensity caregiving on caregivers' mental health and continuation of caregiving. *Health Economics Review*, 7:15.

Study Aim/Purpose: This study sought to measure the impacts of high intensity caregiving for older adults on informal caregivers' mental health and continuation of caregiving as well as how those outcomes varied by level of caregiving intensity, certain caregiver characteristics, and receipt of respite.

Summary of Methods: The author analyzed data collected from the nationwide five-wave panel Longitudinal Survey of Middle-aged and Elderly Persons conducted by the Japanese Ministry of Health, Labor and Welfare. The main dependent variable was distress, measured using the Kessler 6 non-specific distress scale – a 6-item, 5-point scale questionnaire yielding an index of distress ranging from 0 to 24. The intensity of caregiving was defined by the number of hours of informal caregiving provided per week. Caregiver characteristics examined included their work status (regular employees, irregular employees, and non-working caregivers) and whether they live with the older adult for whom they are providing care. The dichotomous proxy variable constructed to represent respite care receipt was receipt of any formal care.

Summary of Key Results: The study found that caregivers who provide high intensity caregiving (20-40 hours per week) tended to continue with it to a greater degree than did caregivers who provide ultra-high intensity caregiving (40 hours or more per week). High-intensity caregiving was associated with worse mental health among non-working caregivers, but did not have any effect on the mental health of irregular employees. Among non-working caregivers, high intensity caregiving did not tend to last more than three years. Further, receipt of formal care (the study's proxy measure for respite care) by non-working caregivers was significantly negatively related to mental distress, indicating that respite care was useful to reduce stress among non-working caregivers.

Study Limitations (as cited by authors): While no limitations to the study were cited by the author it should be noted that the study's use of a proxy measure for respite care, without descriptors of dose or care type, limits the generalizability of this study's positive findings of the protective impact of respite care receipt and caregiver mental distress.

Authors' Discussion/Conclusions: The author suggests that the strong association between family caregiving and mental distress suggests that supporting family caregivers is an important public health issue and supporting non-working intensive caregivers "should be a priority public health issue." The author called for further research, including further analyses of Japan's longitudinal panel surveys, to determine the impact of availability and use of respite care on caregivers' employment status and mental distress.

6. Leggett, A.N., Liu, Y., Klein, L.C. and Zarit, S.H. (2016). Sleep duration and the cortisol awakening response in dementia caregivers utilizing adult day services. *Health Psychology, 35* (5): 465-473.

Study Aim/Purpose: This study examines the effect of sleep duration on the cortisol awakening response (CAR) and whether use of adult day service respite can counteract that negative effect.

Summary of Methods: The study followed 158 family caregivers who lived with individuals with dementia who were attending ADS at least two days a week. Each respondent completed an initial in-person interview to collect background information; engaged in daily evening telephone interviews when they reported information they documented in daily diaries about their health, well-being, and daily care and non-care related activities; and provided five daily saliva samples to measure cortisol awakening response (CAR), defined as the extent of change in cortisol levels from awakening to 30 minutes after awakening and total daily cortisol output measured as cortisol area under the curve with respect to ground (AUC-G). The key measures analyzed for this study were CAR and cortisol levels, sleep duration, overnight care-related stressors, and depressive mood symptoms.

Summary of Results: The study found that sleeping shorter than one's average duration and having less depressive mood were associated with larger CAR. On non-ADS days there was a significant association between length of caregiver sleep beyond his or her average sleep length and a smaller (or "blunted") CAR. Attending ADS the day before had no significant positive effect on the CAR. However, on the morning of ADS use days, regardless of how much longer than average a caregiver slept, cortisol increases were observed. Statistical analysis models adjusted for many covariates found no significant effects of any covariates on the relationship between ADS use and the CAR.

Study Limitations (as cited by authors): The authors recognize the selection bias of the study given that participants self-selected to use ADS and were available to participate in the intensive data collection for this eight-day study. They also note that this report did not include any objective measures of sleep time, and its self-report measures of sleep durations may overestimate total sleep time.

Authors' Discussion/Conclusions: The authors suggest that the overriding effect of ADS on the association between prolonged sleep and a maladaptive CAR pattern indicates that respite interventions have a key role in providing physiological recovery for caregivers. They conclude that providing caregivers with respite may have positive effects on starting the day with proper arousal and energy, and may reduce burden, allostatic load and poor health outcomes. They also suggest that given the importance of sleep duration for health, ADS programs may consider offering sleep hygiene programs to improve sleep of both people with dementia and their caregivers. The authors also recommend future research on the mechanisms through which ADS can moderate associations between sleep and cortisol regulation.

7. Liu, Y., Almeida, D.M., Rovine, M.J., and Zarit, S. (2018). Modeling cortisol daily rhythms of family caregivers of individuals with dementia: Daily stressors and adult day services use. *J Gerontol B Psychol Sci Soc Sci*, 73 (3): 457-467.

Study Aim/Purpose: This study examined associations between the timing of adult day service (ADS) use and the trajectory of daily cortisol levels as a biomarker for stress among caregivers of individuals with dementia who experience chronic stress.

Summary of Methods: The study involved 165 family caregivers who live in the same household and care for individuals with dementia and use ADS programs at least two days per week. Each participant had an initial interview to collect background information. The caregivers were also asked to complete a daily diary. Daily evening interviews collected information compiled in those diaries on daily ADS use that day, care-related stressors, non-care stressors and positive events of each day as well as caregivers' daily sleep quality, duration and wake up time. They also were asked to collect five saliva samples a day to measure their daily cortisol trajectory. The authors tracked the caregivers' cortisol levels in relation to the timing of receipt of ADS and examined other covariates to determine if these mediated the impact of ADS use.

Summary of Results: Stressor exposures among caregivers of individuals with dementia were associated on a daily level with increased cortisol levels before bed. Additionally, daily ADS use was associated with a more robust cortisol awakening response and a steeper decline in cortisol starting from 30 minutes after waking, which can benefit a person under chronic stress. On non-ADS use days, however, caregivers tended to have a flatter diurnal pattern of cortisol levels. Additionally, more ADS use days were associated with a slight but significant increase in cortisol later in the day. Controlling for caregiver characteristics, such as age, gender, and duration of care, all significant positive ADS effects on the caregiver's diurnal cortisol levels remained. Additionally, ADS use had a significant positive effect on the diurnal cortisol slope when the covariates of stressors or positive experiences were controlled for at both the daily and person levels.

Study Limitations (as cited by authors): Authors pointed out that the fixed time windows for salivary samplings did not allow for aligning the timing of stressor exposure to cortisol diurnal rhythms. Additionally, the relatively demanding nature of the data collection meant that the respondents were not likely typical of the broader population of family caregivers of individuals with dementia and thus the findings not generalizable.

Authors' Discussion/Conclusions: The authors highlight the findings associating a more robust CAR slope with days of ADS use days as a biomarker indicating that ADS use provides caregivers partial relief from the primary stressors of care receivers' behavior problems. The authors suggest that future studies examine the effects of a longer time period of ADS use on the cortisol awakening response and the initial morning decline of cortisol as well as on other daily biomarkers of the stress response and long-term health.

8. Lund, D.A., Utz, R.L., Caserta, M.S., Wright, S.D., Llanque, S. M., Lindfelt, C., Shon, H., Whitlach, C. J., Montoro-Rodriguez, J. (2014) Time for Living and Caring: An intervention to make respite more effective for caregivers. *Int'l J. Aging and Human Development*, 79 (2) 157-178.

Study Aim/Purpose: This pilot study presents the rationale for a description of a promising intervention to enhance the effectiveness of respite services for family caregivers. The intervention pilot tested, *Time for Living and Caring (TLC)*, is founded on the understanding that respite, to be effective, should allow caregivers to tend to their own wellness, relationships, and other aspects of their daily lives that have been neglected due to their overwhelming caregiving tasks.

Summary of Methods: The *TLC* intervention is based on the principles of the Selective Optimization of Compensation human development model. The intervention has specially trained service providers individually coaching caregivers on how to: 1) identify their unique circumstances, needs, and resources; 2) select individually tailored use goals for respite based on their priority needs and constraints; and 3) implement strategies for successful goal attainment.

The study was tested with a convenience sample of 20 existing respite users, including four African Americans, three Latinos, and 13 Caucasians. Fourteen caregivers were randomly assigned into the intervention condition and six into the control condition. Those in the control group completed a pre- and post-survey to determine their satisfaction with respite time use and their perceived burden, depression, and experiences with caregiving. Of the 14 in the treatment group, seven were assigned to receive five weekly sessions with a facilitator and seven were assigned to receive three sessions held every other week. During each intervention session, participants completed surveys measuring their satisfaction with respite time-use, level of goal attainment and perceptions of caregiver burden, and satisfaction with caregiving.

Summary of Results: The empirical quantitative results, while not large enough to conduct statistical analysis, were suggestive of the intervention's potential effectiveness. Those in the control group did not have changes in reported satisfaction with respite time or perceived satisfaction with caregiving experiences, and their burden levels showed a slight increase. While the intervention group showed a slight improvement over the short intervention period in their satisfaction with respite time-use, a slight reduction in burden levels, although no notable changes in their satisfaction with caregiving. Qualitative results provided further evidence that participating caregivers found value in the intervention in that they recognized benefits to planning how they wanted to spend their respite time and setting specific goals empowered them to act on their preferences for time-use. In addition, the qualitative information revealed that the activities caregivers enjoy doing during their respite time varies greatly, reflecting the need for each caregiver to prioritize respite time-use based on their individual needs and circumstances.

Study Limitations (as cited by authors): The authors acknowledge that the small pilot does not allow for quantitative analysis of the intervention's outcomes nor can the qualitative data be used to confirm the benefits of the intervention. However, the mixed-methods findings do affirm that the *TLC* intervention

model, used as an individualized approach with trained facilitators, can help caregivers effectively engage in respite activities that best match their unique needs and desires.

Authors' Discussion/Conclusions: Based on pilot study results and the authors' past research documenting that respite is more effective in improving caregiver well-being when caregivers use the time as desired, they conclude that the TLC intervention and approach shows promise as an add-on to respite. They stress the need for an intervention such as TLC that can improve caregiver outcomes regardless of respite care type (such as adult day centers, extended care, and in-home respite) or whether it is formal or informal respite. They also point out that respite service with TLC is an excellent complement, not a substitute for other sources of help for caregivers because it can provide the time needed for caregivers to acquire the other services and assistance needed, such as legal help, financial help, educational skill building resources, counseling, or self-care. It also provides time for caregivers to maintain employment outside the home, seek social or leisure activities, or pursue hobbies and other interests that may have been interrupted by their heavy caregiving responsibilities.

The authors also point out that because the TLC intervention allows for variability in caregiver circumstances, it should be equally effective for racially and ethnically diverse caregivers because it allows all caregivers to select respite time activities that are specific to their own cultural preferences.

Finally, the authors recognize that the TLC model tested in the pilot used a highly resource-intensive one-on-one approach with a trained facilitator that may not be feasible for widespread replication. They point to future research with planned randomized trials of the resource-intensive TLC model that holds promise for informing future development of more cost-effective approaches for delivering the intervention in the future.

9. Mensie, L.C. and Steffen, A.M. (2010). Depressive symptoms and use of home-based respite time in family caregivers. *Home Health Care Services Quarterly*, 29: 120-137.

Study Aim/Purpose: This study investigated the relationship between how family caregivers used in-home respite time and subsequent symptoms of depression. Specifically, the study sought to determine whether there were different effects of respite time used by caregivers for “pleasant activities” versus respite times used to catch up on non-caregiving chores.

Summary of Methods: The study collected information from 74 family caregivers who were living with older adults diagnosed with cognitive impairment or requiring assistance with at least two activities of daily living (ADLs) and receiving 4 hours of in-home respite care from the Caregiver Support Program of a Midwestern Area Agency on Aging (AAA). Information on past use of respite services was obtained from the AAA administrative data. A caregiver questionnaire and telephone interview provided information on the following contextual variables: demographics of caregivers and care recipients; the care recipient’s functional impairment and frequency of behavioral problems; and information on receipt of non AAA caregiving assistance in the past month. Caregivers were also asked to report the amount of time spent on a typical in-home respite day in both discretionary activities (i.e., family interaction, social interaction, religious activities, reading, listening to the radio, watching television, recreation/leisure, and rest/relaxation) and non-care related household chores. Caregiver depressive symptoms were measured using the CES-D 20-item self-report measure.

Summary of Results: The authors found no significant relationship between contextual variables, care recipient functional impairment and level of behavioral problems or caregiver use of respite time for discretionary activities with caregiver depression level. However, they found a modestly significant relationship between the use of respite time to accomplish non-care related chores and lower levels of caregiver depression, even after controlling for the effects of contextual variables, care recipient functional and behavioral problems, and dosage of respite and prior use of respite.

Study Limitations (as cited by authors): Authors suggested that the lack of relationship between caregiver discretionary time and depression may be due to the fact that when caregivers receive only 4 hours of respite per week, they may prioritize doing chores during respite time and have little opportunity to pursue discretionary activities.

Authors’ Discussion/Conclusions: Authors pointed out that the study does not confirm the directionality of the relationship between respite time spent on chores and depression. That is, caregivers with fewer depressive symptoms may be those who have more energy to complete chores and those with greater depressive symptoms may have less energy and motivation to carry out non-care related chores during respite time. They also note the practical implication of their findings suggesting that advice to caregivers about the benefits of respite should have a balanced emphasis on using the time for pleasant activities with the advantages of catching up on household obligations that they may fall behind on because of the demands of caregiving.

10. Roberts, E. and Struckmeyer, K.M. (2018). The impact of respite programming on caregiver resilience in dementia care: a qualitative examination of family caregiver perspectives. *Journal of Health Care Organization, Provision and Financing*, 55: 1-11.

Study Aim/Purpose: The three main study research questions were: (1) What was the determining factor in the transition to the role of family caregiver?; (2) In what ways do awareness of respite programming and actual utilization of respite impact resilience outcomes?; and (3) If the use of respite programming has impacted resilience for the caregiver, how has this translated to improved outcomes for the care recipient?

Summary of Methods: This qualitative research was the second phase of a larger mixed-method study of family caregivers who were using or had in the past used some form of respite services (voucher programs, adult day care, overnight respite, support groups or counseling for the caregiver). A total of 33 individuals participated in a semi-structured interview that asked the caregiver's perspective on: their needs, strengths and resources; emotional and physical functioning of the caregiving dyad; the caregiver's ability to help meet the needs of the care recipient; and caregiver interactions and relationships with health care teams and/or long-term care systems. A qualitative thematic analysis of the transcripts was conducted by the 3-person research team to identify overarching themes and organize the findings for each theme.

Summary of Results: Key themes identified from the research were as follows:

- 1) Family dynamics play a major role in determining who takes on the caregiver role and that when taking on this role, most family members feel they should do it on their own without help, despite not knowing how to handle difficult situations that would come up;
- 2) Caregivers go through financial struggles and finances and red tape pose barriers to secure respite services;
- 3) Seeking out respite helped the caregivers' resilience which they said in turn positively impacted the well-being of the care recipient;
- 4) Support or counseling services helped reduce caregivers' feeling of isolation; and
- 5) Respite time helped caregivers better understand and gain acceptance of their caregiving role, which helped them address the frustrations of caregiving through strength and resilience.

Study Limitations (as cited by authors): The authors emphasize that their research is exploratory with a small sample size.

Authors' Discussion/Conclusions: The authors intend to use the qualitative findings to develop a more rigorous multistate longitudinal study that can determine the relationships of each of the respite program types to caregiver resilience. They emphasized that research on dementia caregiving will be most useful to policy and programming and serving families more effectively if it can illuminate what is working and why, while also defining structural and institutional solutions for building and sustaining familial resilience.

11. Tomita, N., Yoshimura, K., and Ikegami, N. (2010). Impact of home and community-based services on hospitalisation and institutionalization among individuals eligible for long-term care insurance in Japan. *BioMed Central Health Services Research*, 10: 345

Study Aim/Purpose: This study examined the effect of use of home and community-based services for the elderly on their admission to a hospital or residential care facility.

Summary of Methods: This study used a retrospective cohort design and analyzed linked health insurance and long-term care insurance (LTCI) claims data for 565 adults from two farming communities in Hokkaido, Japan. The key outcomes measured after initial date of LTCI certification were time to hospitalization (above a minimum threshold expenditure to exclude short episodes of hospitalization) and time to admission to a group home for the elderly with dementia or other residential care facility for the elderly. The effect of home and community-based services use on these outcomes was analyzed looking at this dependent variable in three ways: (1) average monthly total home and community-based services expenditures; (2) the use or non-use of each of the following types of home and community-based services: home-help, visiting nurse, management and guidance, day care, day rehabilitation, respite care and rental services for assistive devices; and (3) average monthly expenditures for home-visit and day care types of services, use or non-use of respite care, and use or non-use of rental services for assistive devices. Recognizing that the presence of a disease and its severity at the time of the individual's first certification for LTC could be confounding factors, the authors adjusted the analysis for outpatient medical expenditures as a proxy for the severity of illness.

Summary of Results: The authors found that the elderly with low, medium or high expenditures for home and community-based services were less likely to be hospitalized or institutionalized than the non-users of home and community-based services. Among the types of home and community-based services, the strongest association with reduced hospitalization and institutionalization was found among users of respite care and users of rental services for assistive devices.

Study Limitations (as cited by authors): The authors note that the results were biased due to residual and unmeasured confounding factors, including factors for which the data were not available, such as the presence or absence of family members living with the individual who may provide support. They also indicated that because the study was conducted only in farming communities and thus not generalizable to urban areas or other regions of the country.

Authors' Discussion/Conclusions: In explaining their results, the authors suggest that home and community-based services, particularly respite care, reduce the care burden of caregivers, thus allowing caregivers to maintain their ability to provide care.

12. Washington, T.R. and Tachman, J.A. (2017). Gerontological social work student-delivered respite: A community-university partnership pilot program. *Journal of Gerontological Social Work*, 60 (1): 48-67.

Study Aim/Purpose: This study analyzes satisfaction with a small short-term pilot home-based respite program intended to fill a service gap for dementia caregivers.

Summary of Methods: The authors used a qualitative research design, analyzing caregiver responses from pre- and post-intervention semi-structured caregiver interviews to assess satisfaction with the Houseguest program. This program implemented by Masters-level social work students at the University of Georgia provided 7 respite hours in four home visits for caregivers of older adults. Thematic analysis identified common themes in three broad categories: meeting caregiver needs, meeting care recipient needs, and perception of program components.

Summary of Results: Qualitative analysis produced the following themes related to the respite program meeting caregiver and care recipient needs.

Meeting caregivers needs. In post-intervention interviews all caregivers said the program provided some needed respite. Caregivers used their respite time to perform self-care activities, such as gardening, cleaning, relaxing or attending to work obligations. Some caregivers also highlighted the written materials provided by the program as providing needed information (e.g. “tips” or “insight”) on caregiving. Caregivers also explained their need for no-cost supportive services and appreciated that Houseguest did not require a fee.

Meeting care recipient needs. In the pre-intervention interviews, caregivers described limited socialization opportunities for their care recipients. Post-intervention, caregivers said the program directly addressed this need and the care recipients were helped to “feel good about” themselves. Caregivers also liked the tailored activities that were provided based on their care recipient’s interests and abilities. Multiple caregivers indicated that the tailored activities promoted positive behavior, specifically calmness, of the care recipients.

Study Limitations (as cited by authors): The authors note that the study’s key limitation is the small size and lack of diversity in the sample.

Authors’ Discussion/Conclusions: Based on this study’s preliminary evidence of Houseguest’s positive impact, the authors recommend that future research involve multiple sites to determine under what community conditions Houseguest would be most effective and the university infrastructure that would be required to support and sustain the program. The authors propose a model for future research in dementia caregiving that is embedded in community-engaged scholarship that specifically involves community stakeholders and students to test and implement programming within community practice settings, and involves the staff at these settings in the program design.

Added in 2020

1. Leggett, A.N., Meyer, O.L., Bugajski, B.C., Polenick, C. (2020). Accentuate the positive: the association between informal and formal supports and caregiving gains. *Journal of Applied Gerontology*, April 24; 1-9. DOI: 10.1177/0733464820914481

Study Aim/Purpose: This study explored whether receipt of formal and informal supports by caregivers for persons living with dementia (PLWD) were associated with caregiver gains, such as perceived benefits of the caring role or other positive influences on the caregiver's life. The research also assessed whether the positive effects of caregiving differ between women and men.

Summary of Methods: The study employed a cross-sectional design using secondary data from the National Study of Caregivers (NSOC), which interviewed caregivers for Medicare beneficiaries 65 years of age and older who responded to the National Health and Aging Trends Study. Inclusion criteria resulted in interview responses from a total 705 NSOC caregivers of PLWD. Independent variables were three informal and three formal support resources: informal supports included having friends or family to talk to about important things in life, help with daily activities, and help in care provision, and formal supports were support groups for caregivers, respite services, and a training program that helped the caregiver take care of the recipient. The outcome was caregiver gains, measured with a mean score on a four-item Likert scale affirming whether caregiving: 1) "gives confidence in your abilities", 2) "helps you deal better with difficult situations", 3) "helps bring you closer to the care recipient", and 4) "helps you feel satisfied that your care recipient is well cared for."

Summary of Results: The most commonly reported informal support was having friends and family to talk to (86.2%), followed by having friends and family to help with the care recipient (76.5%) and friends and family to help with household activities (55.7%). Receipt of formal supports was much less common with only 21.6 percent having used a respite service in the past year; 8.7 percent having received a care training; and 5.3 percent having attended a support group. The analysis found that both female and male caregivers who provided more ADL assistance and had friends and family to talk to reported more caregiving gains. Those with lower education also had more caregiving gains associated with support than those with higher education. At the same time, none of the formal supports had a significant effect on caregiving gains. However, having attended a caregiver training program was associated with greater caregiving gains for male caregivers but not female caregivers.

Limitations of Study: The authors note that the small number of caregivers utilizing formal supports may limit the power to detect significant associations between service utilization and caregiver gains and may bias or overestimate the gains for men. Additionally, given that it was a cross-sectional design, the study cannot imply that supports lead to positive outcomes for caregivers. They also recognize that the survey does not include information on when in the past year or for how long caregivers used the support services, the intensity of their informal supports, or the size of their networks. Finally, they note that the measure of caregiving gains was limited to a small number of questions.

Authors' Discussion/Conclusions: The authors highlight the findings that support from family and friends can help all caregivers, and for men in particular, skills-based programs may lead to more

caregiving gains. They suggest that future research consider how to best target and recruit male caregivers in training programs, for example, through local service clubs or primary care and other practitioners who work with the care dyad. The authors also point out the lack of racial data in the NSOC survey data they analyzed, and recommend that future research consider racial differences in caregiver gains and supports. Finally, in recognition of the small scale of measures available in NSOC to analyze caregiver gains, they recommend that future studies use a more robust measure of caregiver gains.

2. Parker, L.J., Gaugler, J.E., Samus, Q., and Gitlin, L.N. (2019). Adult day service use decreases likelihood of a missed physician's appointment among dementia caregivers. *J Am Geriatr Soc*, 67: 1467-1471.

Study Aim/Purpose: The study examined the association between adult day services (ADS) use for community-dwelling persons with dementia and a missed physician's appointment among their family caregivers.

Summary of Methods: The authors conducted secondary analysis of baseline data collected for two randomized controlled trials evaluating behavioral interventions for community-living persons with moderate-stage dementia (Advancing Caregiver Training and Care of Persons with Dementia in their Environments). The sample consisted of 509 English-speaking adult family caregivers who were living with the person with dementia and providing at least four hours of daily care. A missed physician appointment in the past six months was the primary outcome assessed. Predisposing factors examined included race, education, and whether the caregiver was a spouse. Enabling factors assessed included adult day service use, social support, and employment status of the caregiver. The medical needs of the caregivers were assessed by self-report of the number of chronic health conditions of caregivers using the 13-item National Health Interview Survey, and psychological needs were assessed by measuring caregiver burden using the 12-item Zarit Burden Interview Short Form.

Multivariate logistic regression analyses were used to identify the predisposing, enabling and need factors associated with a missed physician appointment, adjusted by an interaction term between race and ADS use to examine if racial differences in adult day service use were associated with a missed physician's appointment.

Summary of Results: Thirty-seven percent of the sample used adult day services. Caregivers who utilized ADS were 49 percent less likely to miss a physician's appointment compared to those who did not use these services. Regardless of ADS use, black caregivers were more likely than white caregivers to miss a physician appointment. Older age was associated with decreased odds of missing an appointment. Additionally, caregivers with more chronic health conditions were more likely to report that they had missed a physician's appointment than those with fewer chronic health conditions.

Limitations of Study: The authors note several limitations of this study. First, the study relied on a convenience sample of caregivers who had volunteered for the trial and thus may have been more likely to use ADS or similar services. Second, the analysis, that was based on self-report of ADS use and missed appointments, may have been subject to recall bias. Third, generalizability of the findings to rural caregivers may not be applicable since the study sample primarily included an urban population.

Authors' Discussion/Conclusions: Findings indicate ADS use may offer caregivers respite to attend medical appointments. The authors recommend that ADS programming be expanded to encourage health-promoting behaviors among caregivers. For future research, the authors recommend studies to examine if ADS use is associated with other positive health behaviors among caregivers. Additionally, the authors recognize the cultural and access barriers that black caregivers may face in accessing health

care and recommend that home and community-based services both improve their access to adult day services and provide the support needed to help them attend to their own self-care.

3. Sakurai, S. and Kohno, Y. (2020). Effectiveness of respite care via short-stay services to support sleep in family caregivers. *Int. J. Environ. Res. Public Health*, 17: 2428-2438.

Study Aim/Purpose: Conducted in Japan between July 2015 and February 2017, this study analyzed the effects of “short-stay services” (i.e., one or more nights of overnight respite care) on the sleep of family caregivers living with an older person with dementia or with nocturnal awakening.

Summary of Methods: A total of 17 caregivers began the study and seven had to be excluded, leaving a final study sample of 10 for the analysis. Participants completed a self-administered questionnaire one week prior to the first test day and at subsequent visits. The survey included caregiver demographic information, number of cohabitants, height, weight, lifestyle habits, health status, Pittsburgh Sleep Quality Index (PSQI) score, and length of the caregiving period. For one night after a caregiving day and one night during receipt of respite care, participants were asked to keep a sleep journal on the day following the study night. These provided supporting data in the sleep time/wake time analysis. Before going to sleep, each participant wore a fitted actigraph on their wrist as well as a heart rate sensor. The sleep variables determined with the actigraph were bedtime, wake-up time, duration of sleep time, sleep efficiency (sleep time/time in bed x 100), sleep latency (minutes between going to bed and sleep onset), and awake time between sleep onset and wake time. A heart rate sensor fixed to a specified site recorded heart activity during sleep and the results were quantified into high frequency (HF) and low frequency (LF). LF/HF was used as an index for cardiac sympathetic nervous activity balance. A higher LF/HF value indicated increased cardiac sympathetic nervous activity. Measurements were taken every five minutes for the whole night and totaled for the first and second half of the sleep time.

Summary of Results: No significant differences in actigraph findings were found between caregiving and respite days. While the study participants had relatively high sleep efficiency, sympathetic nervous activity measurement revealed that the LF/HF value for the first half of the sleep period on the caregiving day was near the upper limit of standard range and PSQI scores from surveys exceeded those of the sleep disorder screening criteria. On respite care days, caregivers’ LF/HF value was significantly lower during the first half of the sleep period compared to nights after caregiving days. The authors note that on respite nights the LF/HF value for the first half of the sleep period was approximately the same level as reported among non-caregivers in other studies. Researchers found an even greater reduction in the LF/HF value on respite days among working caregivers compared to those who were not working.

Limitations of Study: The authors acknowledged the limited generalizability of the study findings due to the small sample size and the limited duration of data collection (one night) for both conditions.

Authors’ Discussion/Conclusions: Despite the study’s recognized limitations, the authors conclude that the objective data on autonomic nervous activity during sleep provide important evidence of the value of short-stay services in supporting improved sleep quality for caregivers. Given that family caregivers of older people who need care often experience sleep disorders and that the triggering of sympathetic nervous activity is associated with elevated blood pressure and related health problems, regular use of respite care may not only improve sleep quality for caregivers, but may also improve their health and quality of life by reducing risk of cerebral and cardiovascular disease.

4. Vandepitte, S., Putman, K., Van Den Noortgate, N., Verhaeghe, S., Annemans, L. (2019). Effectiveness of an in-home respite care program to support informal dementia caregivers: A comparative study. *Int J Geriatr Psychiatry*, 34: 1534-1544.

Study Aim/Purpose: The aim of this study was to assess the effectiveness of a 24-hour in-home respite care program in supporting informal caregivers of persons with dementia residing in the community.

Summary of Methods: This study used a pre/post prospective quasi-experimental design to compare differences in caregiver outcomes between caregivers participating in the intervention and those receiving standard dementia care (including medical, psychological, and other health and social services) and other supportive services, but not respite care. The intervention, conducted by Alzheimer Belgium, consisted of at least 5 days of 24-hour respite provided at no cost by a trained employee. The program also included caregiver support by having the respite employee track all daily experiences and offering strategies to better deal with patients' difficult behaviors described in the diaries.

The final sample size for the analysis included 76 dyads in the treatment group and 73 in the comparison group. Data were collected from study participants through in-person interviews at baseline and 6 months later, with a telephone interview with the treatment group 14 to 15 days after the last intervention day. The baseline interview collected characteristics of the caregiving dyad and the patient's resource use. At baseline and at the two post-intervention points, information was collected for the primary outcome of caregiver burden (measured using the Zarit Burden 22-item Likert scale instrument), as well as caregivers' self-perceived health-related quality of life (using the EQ-5D-%L), frequency of behavioral problems in the dementia patients, the impact of those behaviors on the caregiver (measured with the Revised Memory and Behavior Problems Checklist), and desire to institutionalize the patient (measured with a modified version of the "Desire-to-Institutionalize" scale, identified as a reliable predictor for future institutionalization). At baseline and 14-15 days post-intervention the caregivers in the treatment group were also asked about the level of strain of caregiving and the burden on their social and family life.

Summary of Results: After six months there was no significant difference on caregiver burden, health-related quality of life, or reported frequency or impact on the caregiver of patient behavioral problems. However, the intervention group had a significantly lower desire to institutionalize both shortly after the intervention and at six months post-baseline. Shortly after the intervention, intervention group caregivers also reported significantly lower role strain and a lower burden on social and family life compared to their baseline reports. At the same time, frequency of behavioral problems and their impact on the caregiver was not significantly different for the intervention group between baseline and post-intervention, indicating little impact of the intervention on this area. There was also a nonsignificant trend in improved health-related quality of life for caregivers in the treatment arm.

Limitations of Study: The authors listed several limitations of the study. First, as with all non-randomized experimental designs, there remained a possibility of risk to internal validity because of confounders not measured in their propensity score matching of the treatment and control groups at baseline. They also noted that participants with lower socioeconomic status were underrepresented in

the study sample. A final limitation noted was the variance in duration of respite care provided to the intervention group based on each household's needs.

Authors' Discussion/Conclusions: In their discussion of findings, the authors highlight the methodological strengths of their quasi-experimental design in minimizing bias and point to the practical and ethical difficulties of conducting randomized controlled studies of respite interventions. The authors highlight the importance of the study findings on the decrease in desire to institutionalize six months after receipt of extended overnight in-home respite care. Given that this measure has been found to be a valid proxy for predicting time to actual placement in institutional care, the authors highlight the intervention's potential effectiveness in improving patient quality of life, reduced morbidity, and reduced health care costs, which are all associated with in-home versus institutional long-term care.

5. Verbakel, E., Metzelthin, S.F., Kempen, G.I.J.M. (2018). Caregiving to older adults: Determinants of informal caregivers' subjective well-being and formal and informal support as alleviating conditions. *J Gerontol B Psychol Sci Soc*, 73 (6) 1099-1011.

Study Aim/Purpose: This study investigated the association between caregivers' subjective well-being and the health status of their care-receiver, hours of informal caregiving they provide, and the reported burden of caregiving. The study also examined how supports—both formal and informal—used by caregivers mediate or buffer against diminished caregiver well-being.

Summary of Methods: The authors conducted secondary analysis of interview data from 4,717 dyads of informal caregivers and their older care-receivers from the *Older Persons and Informal Caregivers Survey Minimum Dataset* (TOPICS-MDS survey), collected between 2010 and 2013, as part of the Netherlands' National Care for the Elderly Programme. Care-receiver health status indicators or "primary stressors" measured were cognitive impairment, functional disability, and problem behaviors (a scale to measure the extent of problems the caregiver experienced due to the care-receiver's demanding or unusual behaviors). The intermediate outcomes of focus were hours of informal caregiving and caregiver burden. Burden was assessed as a scale measure of level of strain experienced in caring for or accompanying the care receiver. The long-term or final outcome measured was the subjective well-being of the caregiver, using a scale measure of how happy the caregiver currently felt. Additionally, the study measured use of supports in three categories: 1) professional home care; 2) support from other caregivers or volunteers; and 3) whether the caregiver received "a lot" of support or "no or some support" from family, friends, neighbors or acquaintances.

Summary of Results: With regard to the factors affecting caregiver well-being, the study found that well-being was primarily affected by perceived burden, and diminished caregiver well-being was directly associated with the extent of care-receiver problem behavior. Greater burden was associated with increased caregiving hours, but was also independently affected by all three of the primary stressors examined (i.e. cognitive impairment, functional disability, and problem behaviors of the care-recipient). The number of informal caregiving hours was found to be "especially sensitive" to greater functional disability and problem behavior of the care-recipient.

With regard to the moderating effects of the three types of caregiver supports, the analysis found that caregivers spent fewer hours performing caregiving tasks when professional home care was used or the caregiver reported receiving "a lot" of support from family and friends. There was no similar moderating effect of having supports from other informal caregivers or volunteers. Perhaps contrary to assumptions, use of professional home supports was positively correlated with burden; however, the authors suggest that the use of professional care might be the result, rather than the cause, of the high level of burden.

Limitations of Study: The authors acknowledged several study limitations. First, though their findings point to an interactive relationship among primary stressors, intermediate outcomes, and the final outcome of caregiver well-being, the cross-sectional data cannot be used to implement a longitudinal design. Although all of the data were collected using the same questionnaire, the authors noted that there was great variation in the 21 studies whose interview data were analyzed with regard to sampling frame, inclusion criteria, study design, sample size, and data collection method. A third limitation cited

was the relatively high item nonresponse, though the authors point out that they conducted robustness checks with different treatments of missing values, and these did not alter their conclusions. Finally, the authors recognized that more information on caregiver characteristics would have added to the richness of their analysis. Specifically, they mention that the survey did not include information on other concurrent responsibilities or employment of the caregivers, which could have provided insights into which informal caregivers are most at risk of diminished well-being.

Authors' Discussion/Conclusions: The authors conclude that instrumental support for caregivers, rather than emotional support, is the primary mechanism through which support mediates the negative impacts of the caregiving role. Because professional home care and support from family and friends both result in spending fewer hours providing care, these in turn moderate the difficulties of caregiving and increase caregivers' feelings of well-being (both directly and via reduced burden). At the same time, the authors acknowledge that receipt of supports from other informal caregivers and volunteers was not strongly associated with improvements for caregivers and that this finding has important policy implications. At the time of the study, health reform policies under consideration in Western European nations, including the Netherlands, were emphasizing strengthening informal care and reducing professional home care. The authors suggested the need for research to examine the implications of health care reform policies on the interaction between formal and informal sources of support for caregivers. They also recommended that future research using a longitudinal design could test their theoretical model of factors affecting and moderating caregivers' subjective wellness.

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

1. Caldwell, J. and Heller, T. (2003). Management of respite and personal assistance services in a consumer-directed family support programme. *Journal of Intellectual Disability Research*. 47 (4/5): 252-366.

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

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

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

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

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

2. Chou, Y.C., Tzou, P.Y., Pu, C.Y. Kroger, T. & Lee, W.P. (2008). Respite care as a community care service: Factors associated with the effects on family carers of adults with intellectual disability in Taiwan. *Int Journal of Intellectual and Developmental Disability*, 33 (1): 12-21.

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

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

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

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

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

IV. Studies of the outcomes of respite targeted to multi-age groups

Added in 2018

1. **Ackerman, L. and Sheaffer, L. (2018). Effects of Respite care training on respite provider knowledge and confidence and outcomes for family caregivers receiving respite services. *Home Health Care Services Quarterly*, Feb 9: 1-20.**

Study Aim/Purpose: This article presents the results from a large nationwide evaluation of the *Respite Education and Support Tools* (REST) respite provider training program.

Summary of Methods: The first component of the study was a pre/post design including 895 trainees who participated in 126 different REST training workshops between June 2014 and June 2017 in 18 different states. The pre-training survey collected demographic information and Likert scale questions about perceived respite knowledge and confidence. The post-training survey included objective measures of respite knowledge on ten core areas of respite care. Repeated measures mixed ANOVA tests were performed to analyze changes in knowledge and confidence. The second study component surveyed 102 family caregivers six months after their respite care provider had received training, using a modified version of a respite efficacy questionnaire developed by ARCH. This survey asked caregivers to rate their actual and anticipated wellbeing at 3 time points: 1) before respite; 2) while respite was being received; and 3) if respite were to end. Caregivers were asked to rate their stress level, general health status, opportunities to engage in desired social/recreational activities, and likelihood of placing the care recipient in out-of-home care. The survey also listed 12 common stress-related health symptoms and asked caregivers how many of these they experienced before respite and while receiving respite.

Summary of Results: The authors found significant improvements in respite provider knowledge and confidence after training, regardless of trainees' prior respite experience and professional background. Additionally, 84 percent of respondent trainees achieved satisfactory respite knowledge after training completion. With regard to family caregiver outcomes, the study found significantly lower self-reported stress, general health problem status, and out-of-home placement risk, and more opportunities for caregivers to engage in social/recreational opportunities during the period of respite receipt compared to before respite was received and what caregivers assumed would occur if respite ended.

Study Limitations (as cited by authors): The authors note that the study findings have limited generalizability due to the lack of comparison groups and their use of use of a one-time survey for caregivers to self-report changes in their well-being pre/post provider training.

Authors' Discussion/Conclusions: The authors recommend that researchers, practitioners and policy makers work together to develop programs and policies that reflect the positive findings on REST's effects. They also recommend additional research to examine the effects of varied aspects of respite program delivery on caregiver outcomes, the use of clinical and biomarkers of caregiver stress and health status as well as a focus on how respite care quality impacts the care recipient and larger family system.

2. Institute for Research and Innovation, Shared Care Scotland (IRISS), Coalition of Carers in Scotland, and Minority Ethnic Carers of Older People Project (2012). *Rest assured? A study of unpaid carers' experiences of short breaks.* Dunfermline, Fife, Scotland: Shared Care Scotland.

Study Aim/Purpose: This report explored the benefits, limitations, factors affecting access to and recommendations for improvement to short breaks (also known as respite care) provided by formal services, family, and friends.

Summary of Methods: Findings are based on the responses of 1210 caregivers to a country-wide survey distributed through carer centers across Scotland. The survey was distributed by mail, links on website postings, and other communication channels of the carer organizations. Surveys were also distributed to a random sample of carers served by another organization (MECOPP) to reach minority ethnic and lesbian, gay, bisexual and transgender people. In addition to the survey, qualitative research (focus groups with 36 carers and 13 one-on-one interviews) were conducted using semi-structured protocols. Analysis of results was descriptive, summarizing survey responses and supplementing that information with common themes and quotes from carers based on the qualitative data collection.

Summary of Results: More than one-half (57%) of carers surveyed had not taken a break from caring. Among black and minority ethnic carers, almost two-thirds (63%) had not had a break from caring. Forty-three percent of those who had not had a short break indicated that this was because they did not know how to access short breaks. Other barriers identified included: difficulty with the planning process (including sometimes only being given short notice about respite care availability), a lack of appropriate and personalized care, carers' guilt about giving up the caring role even for short breaks, and uncertainty about eligibility. Among those who had accessed respite, when asked what kind of respite services they used, 57% indicated that they had used "social work services" and half of those carers also used at least one other support (e.g. friends, voluntary organizations, health services, and respite through direct payments). Most carers who had used respite were satisfied with the quality of the break, the choice, the support available to organize it, and the length of respite time provided. Respite users were most commonly dissatisfied with how often respite was provided. Qualitative input indicated that short breaks were fundamental to help alleviate the physical and emotional demands of caring, sustain the caring relationship, and prevent admission to residential care.

Study Limitations (as cited by authors): None mentioned

Authors' Discussion/Conclusions: The authors made the following recommendations for short breaks: improve national and local planning, including the engagement of carers in decisions about the future of short breaks programming; expand information about and access to short breaks; address the challenges and opportunities presented by allowing carers to self-direct the supports they need; help families and communities support one another; improve local data information systems and national performance data, and implement rigorous approaches to measure the reach and impact of short breaks, including a focus on poorly served groups.

Added in 2020

1. **Shepherd, D., Goedeke, S., Landon, J., and Meads, J. (2020). The types and functions of social supports used by parents caring for a child with autism spectrum disorder. *J Autism Dev Disord*, Apr; 50(4):1337-1352.**

Study Aim/Purpose: The purpose of this study was to document the kinds of social support used by parents caring for children with autism spectrum disorder (ASD) and to understand how they characterize the benefits and effectiveness of these supports for them as caregivers.

Summary of Methods: The study design was cross-sectional, utilizing an online survey with parents recruited via email and Facebook posts. Only volunteers who had a child with ASD living with them and residing in New Zealand were included in the study. The study sample included 674 parents, with parent age ranging from 23 to over 70 years, with a mean of 43.91 years, and their children's age ranging from 2 to 47 years, with a mean age of 11.69 years.

In addition to questions about child and parent characteristics, the survey asked parents to document whether or not they used any of 14 types of social supports, including 9 formal supports, 4 informal supports, and social media. The categories of formal supports included several government-funded programs that provide financial support and/or referrals for health, special education or other related services, national autism organizations, respite services, general practitioners, private therapists, and teachers (mainstream or specialized educators). The categories of informal supports were: partners/spouse, immediate family (parents/siblings), other relatives, and close friends. Parents were asked several questions about the function and effectiveness of the supports used. For each support used, respondents were asked a short series of questions to categorize the function of that support for them as "tangible", "emotional", "financial", and/or "informational". To assess the support's perceived effectiveness, respondents were asked to rate whether it was a substantial source of support for them and if it reduced their parenting stress.

Summary of Results: Across the nine formal support types, three government-funded services ranked as the most utilized. Formal supports were used less often by parents of adolescents and adults compared to parents of young children with ASD. Among informal supports, spouses were the most frequently reported type of support used, followed by immediate family and then friends. Social media was listed as a source of support for approximately 45 percent of parents. The significant differences found related to support use and parental characteristics included: parents not currently in a relationship were more likely to utilize respite services and friends as support, but less likely to report support from school teachers; those with less education reported higher utilization of some of the government-funded programs and lower utilization of spouses as informal supports than those who went on to higher education; females were significantly more likely than males to use social media for support; and males were more likely to seek support from two of the government agencies and informal support from their spouse.

With regard to effectiveness, overall parents rated informal sources as more effective for them than formal support types. Within the group of informal supports, spouses received the highest mean ratings

of support. Within the group of formal support types, private therapy was the exception, having the highest level of tangible and informational support among the formal supports used. Though it is noteworthy that private therapy was significantly more likely to be used by parents who attended university than those who did not, the authors point out that these parents may have more access to the financial resources to pay for this kind of support. While not as highly rated for effectiveness as informal supports overall, social media was rated the highest of all the support types for emotional support and equally as high as spouses for providing tangible and informational support.

Limitations of Study: The authors acknowledged that the sample overrepresents well-educated European females, thus limiting the generalizability of the study findings. They also note that the specificity of the formal supports studied to those offered in New Zealand may limit their study's generalizability to other countries. Additionally, recruitment of study participants through Facebook groups of national ASD organizations may have limited study participation among parents of children with ASD who are not members of those organizations. Lastly, the authors suggest that the category of immediate family support as they defined it may have been too broad and could have different findings if it had been more narrowly defined to focus on the participant's parents and children.

Authors' Discussion/Conclusions: The study findings indicate that informal supports have greater functionality and value than formal supports for parents of children with ASD. The findings are also novel in demonstrating the benefits of social media platforms that involved virtual interpersonal exchanges for parents of children with ASD. Given the importance of information supports, the authors recommend that research is needed to understand how social supports are established, maintained and disrupted for this group of parents.

V. Studies of Veterans' Administration Program of Comprehensive Assistance for Family Caregivers (PCAFC)

Added in 2018

1. Shepherd-Banigan, M., et al. (2018). Comprehensive support for family caregivers of post-9/11 Veterans Increases Veteran Utilization of Long-term Services and Supports: A Propensity Score analysis. *Journal of Health Care Organization, Provision, and Financing*, 55: 1-12.

Study Aim/Purpose: This study examined trends in the use of VA-purchased long-term services and supports (LTSS) to determine whether there is an association between participation in the Veterans' Administration (VA)'s *Program of Comprehensive Assistance for Family Caregivers (PCAFC)*¹ and Veteran use of home and community based services (HCBS) and institutional LTSS.

Summary of Methods: This study used a quasi-experimental pre/post retrospective cohort design, comparing veteran LTSS utilization at six month intervals for up to 24 months between 15,650 Veterans whose caregivers were ever enrolled in the PCAFC anytime from May 2011 to March 2014 (treatment group) and 8,339 Veterans whose caregivers applied to PCAFC during the same period but were never approved (comparison group). The authors used VA program data and electronic health records to measure changes in the following three key outcomes: (1) use of any VA-provided or VA-purchased HCBS or institutional care; (2) receipt of any VA-purchased HCBS (homemaker home health care services, skilled home health care, adult day health care, hospice or respite care services); and (3) receipt of any care in a VA skilled nursing facility, community nursing home, State Veterans Home, or medical foster care home. For data analysis, two 6-month intervals of service use data prior to the application were included as the "pre-baseline" period. Baseline for the treatment group was the date of submission of the first approved application to the PCAFC; comparison group baseline was the date of the first submitted application. The post-outcomes were measures at 6-month intervals (up to 24 months total). To address possible confounding effects of the differences between the groups, the authors applied inverse probability of treatment weights constructed using propensity scores, based on the predicted probability of ever being enrolled in PCAFC.

Summary of Results: Veterans whose family caregivers participated in PCAFC had significantly higher relative rates of LTSS use and HCBS use specifically than individuals in the comparison group following program application. The findings were inconclusive with regard to an effect of PCAFC on institutional

¹ PCAFC provides training, services and other types of assistance for family caregivers of post-9/11 era Veterans who need assistance with ADLs or supervision or protection because of the residual effects of their injuries they sustained in the line of duty. Participating caregivers are required to complete a training curriculum and they receive a monthly tax-free stipend ranging from \$600-2,300 per month, based on the Veteran's care needs and number of hours of caregiving each week. PCAFC also provides a generous menu of other benefits and services for caregivers, including health insurance coverage, respite care services and mental health care services for the caregiver.

LTSS use, since at some data collection points LTSS use was higher among the treatment group than the comparison group and at other time periods it was not.

Study Limitations (as cited by authors): The authors note that propensity scoring to weight the treatment and comparison groups did not address all unobserved confounding, including unobserved confounding related to PCAFC eligibility criteria. Other study limitations cited included the limit of 24-months of follow-up to measure impacts, lack of information about care recipients' ADLs, IADLs or cognitive function, and the fact that the authors only had access to data on veterans' LTSS use if it was provided or purchased by the VA health system.

Authors' Discussion/Conclusions: The authors stated that while more research is needed to understand their findings on fluctuating trends on institutional LTSS use, the fact that PCAFC increased the use of HCBS will have very important implications for the VA and how they can connect Veterans to high quality, lower cost HCBS. The authors recommend more research to understand: (1) the longer term impact of support for family caregivers on Veteran LTSS use and costs; (2) Veteran preferences for informal versus formal care and HCBS versus institutional LTSS; (3) the impact of supports for family caregivers on civilian populations that likely face a different set of health concerns and system supports; and (4) the positive and negative burden impacts of HCBS versus institutional LTSS and if they increase burden ways to restructure LTSS to better support family caregiver needs.

2. Van Houtven, C.H., et al. (2017). Comprehensive support for family caregivers: Impact on Veteran health care utilization and costs. *Med Care Res Rev*, 1: 1-27.

Study Aim/Purpose: This study examines the early impact of a Veterans Administration program called the *Program of Comprehensive Assistance for Family Caregivers* (PCAFC).¹

Summary of Methods: This study used a quasi-experimental pre/post retrospective cohort design, comparing veteran health care utilization and costs at six month intervals for up to 36 months between two groups: (1) 15,650 Veterans whose caregivers were ever enrolled in the PCAFC anytime from May 2011 to March 2014 (even if they discontinued enrollment for any reason during the 36 months study period); and (2) 8,330 Veterans whose caregivers applied to PCAFC during the same period but were never approved. The three categories of outcomes measured were: (1) acute care use (including use of emergency department care and inpatient hospitalization for any reason); (2) VA outpatient care use (number of VA outpatient visits, receipt of any VA primary care visit, receipt of any VA specialty care visit, and receipt of any VA mental health care visit); and (3) total health care costs for VA and VA purchased care for the Veteran (including inpatient care, extended care, outpatient care—including emergency department and home-based primary care, and pharmacy costs). Data for the outcome analysis were obtained from the VA electronic health records and related VA accounting systems that maintain health care utilization data. For data analysis, baseline for the treatment group was the date of submission of the first approved application to the PCAFC; comparison group baseline was the date of the first submitted application. The post-outcomes were measures at 6-month intervals (up to 36 months) based on the application date to PCAFC. To address possible confounding effects of the differences between the PCAFC and non-PCAFC participating groups, the authors applied inverse probability of treatment weights constructed using propensity scores, based on the predicted probability of ever being enrolled in PCAFC.

Summary of Results: Both groups had similar emergency department use and in-patient hospitalizations, but PCAFC enrollment was associated with increased use of VA outpatient care throughout the study period for all outpatient measures examined: total outpatient visits, receipt of any VA primary care, receipt of any VA specialty care, and receipt of any VA mental health care. In addition, estimated total health care costs for PCAFC Veterans were \$1,500 to \$3,400 higher per 6-month interval than for the control group. Total VA costs fell over time for both groups, but they remained significantly higher for Veterans whose caregivers has enrolled in PCAFC.

Study Limitations (as cited by authors): The authors note that although the two groups had relative balance in utilization of health care at study baseline, it is possible that there are some other residual differences (that could not be accounted for with the propensity scoring) between the treatment and control groups which impacted outpatient care use and VA health care costs of the treatment group. A second potential limitation acknowledged by the authors is that the availability of outcome data for the 6-month and 1-year intervals post-application were available for nearly all of the study sample, but the outcome data were less available beyond that time period. Thus, the analysis is truly informative only regarding the short-term impacts of the program.

Authors' Discussion/Conclusions: Authors suggest that the study findings of increased outpatient care use and VA health costs indicate that PCAFC may have increased Veterans' short term access to care due to the training and support offered to caregivers, the PCAFC stipend that may have enabled caregivers to make and accompany their care recipients to appointments, the access to health care insurance for caregivers that was provided by PCAFC may allow them to address their own health care needs and thus make it easier for them to help the Veteran access his or her care; and the quarterly home assessment visits required by the program. With regard to future research, the authors conclude that the rigorous methods used in this study, including carefully constructing the best available comparison and using techniques to minimize selection bias, are useful to guide future evaluation efforts of PCAFC and other LTSS programs.

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

1. Ingleton, C., Payne, S., Nolan, M., and Carey, I. (2003). Respite in palliative care: a review and discussion of the literature. *Palliat Med*; 17(7):567-75.

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

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

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

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

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

2. Jeon, Y., Brodaty, H., Chesterson, J. (2005). Respite care for caregivers and people with severe mental illness: literature review. *Journal of Advanced Nursing*, 49 (3): 297-306.

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

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

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

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

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

3. Mason, A., Weatherly, H., Spilsbury, K, Golder, S., Arksey, H., Adamson, J., and Drummond, M. (2007). The effectiveness and cost-effectiveness of respite for caregivers of frail older people. *J Am Geriatr Soc, 55 (2): 290-9.*

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

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

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

Authors' Discussion/Conclusions: The authors conclude that "the existing evidence base does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn" for two principal reasons. First, there are serious problems with the methodological quality of many studies underpinning the evidence base. Second, where better-quality evidence exists, the implications for other populations are unclear." Furthermore, they note that the relative effects found in these studies are highly dependent on how the intervention and comparator services were configured, resourced, delivered, and accessed." The authors recommend pilot studies be conducted to inform full-scale controlled trials and that these studies "identify one or more target groups (i.e. caregiver and care receiver dyads), establish clear definitions of services to be compared, and determine the main outcomes to be measured, such as caregiver quality of life or institutionalization rate." The authors suggest that future research should combine qualitative and quantitative methods.

4. Pinguart, M. and Sorensen, S. (2006). Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18: 4, 577-595.

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

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

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

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

Summary of Key Results: The authors’ outcome specific analysis across all interventions found that the interventions had statistically significant, but small immediate effects on caregiver burden, depressive symptoms, subjective well-being, abilities/knowledge of the caregiver, and symptoms of the care receiver. Studies with follow-ups with an average time lapse of 11 months showed significant positive effect on caregiver burden, depressive symptoms and ability/ knowledge. On the other hand, no significant effect of intervention was found on the risk of institutionalization. When the effect sizes were analyzed for specific kinds of interventions, the analysis showed that psychoeducational intervention had significant effects on all outcomes except institutionalization, with those requiring active participation of the caregivers (e.g. to practice or role-play what they learned) having the broadest effects. Cognitive behavioral therapy (CBT) had a small to moderate positive impact on caregiver burden and a large positive effect on caregiver depression, though the authors note that only one CBT study was available on the impact of CBT on caregiver depression. Counseling showed significant and moderately sized effects on burden, while supportive interventions (e.g. with group support groups)

improved subjective well-being. Training (e.g., on improving memory) of the care receiver had small significant effects on the symptoms of the care receiver. Studies on respite interventions also had small significant effects, specifically on caregiver burden, depression and subjective well-being. “Structured” multi-component interventions did not show significant effects on most of the outcomes, but were significantly related to delayed institutionalization for the care receiver. The authors also found that longer interventions were more likely to improve depression and to decrease the risk of institutionalization.

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

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

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

5. Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S. (2011). The impacts of short break provision on families with a disabled child: an international literature review. *Health and Social Care in the Community*, 19(4): 337-371.

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

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

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

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

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

6. Shaw, C., McNamara, R., Abrams, K., Cannings-John, R., Hood, K., Longo, M., Myles, S., O'Mahony, S., Roe, B., and Williams, K. (2009). Systematic review of respite care in the frail elderly. *Health Technology Assessment*, 13: 20.

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

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

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

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

The separate analysis of qualitative studies found that uptake of respite care was influenced by a variety of factors including: caregiver attitudes toward caring and respite provision; the caregiving relationship; the acceptability to, and impact of respite care on care recipients; hassles resulting from the use of respite care; quality of respite care, and the appropriateness and flexibility of the respite provided. Most common needs reported by caregivers in the qualitative studies were: information about services, support beginning early in their caregiving careers, access to a variety of services and flexibility in how those services are provided, reliable transportation supports, and respite care that provides socialization and stimulation for care recipients, including activities appropriate for their abilities and interests.

Limitations of Studies Reviewed: The authors note that there was a lack of good-quality larger trial studies and that respite interventions studied varied greatly from one another. They noted limited process measures with “poor descriptions of the characteristics of the respite that was provided” and “limited provision and uptake of the respite services that were offered” in the studies. They also noted a lack of economic analyses of respite.

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

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

7. Strunk, J.A. (2010). Respite care for families of special needs children: A systematic review. *J Dev Phys Disabil*, 22: 615-630.

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

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

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

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

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

Added in 2018

1. Broady, T. and Aggar, C. (2017). Carer interventions: An overview of service effectiveness. *J of the Australasian Rehabilitation Nurses' Association*, 20 (2), 5-11

Study Aim/Purpose: This is a summary of caregiver interventions and their effectiveness for the following major types of interventions: (1) information and education, (2) psychoeducation, (3) respite care, (4) counseling, (5) peer support, (6) the use of technology, and (7) multicomponent interventions.

Summary of Methods: The paper summarizes information from 75 research studies and literature reviews/meta-analyses cited as references. Databases or other sources used to identify potential studies for inclusion or specific criteria for study inclusion are not described.

Summary of Key Results (related to studies of effectiveness): Overall, the authors found that the literature to date shows that caregiver satisfaction with interventions is positive, but the effects of any single or combined type of interventions on caring burden, anxiety, stress, mental health and general wellbeing are less conclusive. Overview findings specific to respite services are consistent and suggest respite has small positive effects on caregiver health and level of burden and can have a positive effect on caregiver motivation in their caring roles, reducing fatigue, and improving psychological adjustment. At the same time, respite effectiveness depends on service quality, flexibility and its ability to meet individual family needs.

Limitations of Studies Reviewed (as cited by the author): The authors state generally that outcome findings from their review are inconclusive because there has been limited quality research with methodological rigor on caregiving interventions

Authors' Discussion/Conclusions: The authors note that there is great variability in caregiver problems and support needs and thus differences in caregiving experiences and intervention needs. They recommend that interventions for caregivers include comprehensive assessment, identification of at-risk caregivers and follow-up of individual needs. The authors also call for more rigorous evaluations to determine which types of caregiver interventions work and under which circumstances.

2. Edelstein, H., Schippke, J., Sheffe, S., Kingsnorth, S. (2016). Children with medical complexity: a scoping review of interventions to support caregiver stress. *Child Care, Health and Development*, 43 (3): 323-333.

Study Aim/Purpose: The authors conducted this review to identify and describe the full range of published studies on interventions for reducing the stress of caregivers of children with medical complexity (CMC).

Summary of Methods: The authors conducted a broad systematic “scoping” review of the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ovid Medline, and Embase to identify English language articles published between January 2005 and February 2016 on interventions for familial caregivers of children ages 1-24 with medical complexity. Hand searching of key articles and a general internet search for peer-reviewed articles on the subject were also conducted. Given that there is no common diagnosis defining children with medical complexity, search terms such as complexity, multiple comorbidity, fragility, technology and/or ventilator dependent were used as proxies.

Summary of Key Results (related to studies of effectiveness): Forty-nine studies met the criteria for inclusion. These studies focused on six domains of interventions: care coordination models, respite care, telemedicine, peer and emotional support, insurance and employment benefits, and health and related supports. Across studies there was a wide range of intervention designs, outcomes, and measures used. Eight studies examined respite care for CMC that provide in-home nursing care or out-of-home hospice-type services. Studies found significant reductions in parental stress and increases in how parents were able to cope with caregiving duties if they received breaks from respite services along with assistive technology. At the same time, one study found the benefits of respite were negated if the respite care provider was not familiar and knowledgeable of the child’s needs. Several qualitative studies explored parental perceptions of different respite models and concluded that building trust was a key concern of family caregivers if the same staff were not consistently assigned to a family or if access to services was not dependable.

Limitations of Studies Reviewed (as cited by the author): The authors noted that their ability to summarize findings from the review was limited because of the studies’ small to medium sample sizes. Additionally, they suggest their search may have missed some published work if the target population of CMC and outcomes were not well described.

Authors’ Discussion/Conclusions: The authors conclude that published studies show there is promise for reducing the stress of families who care for CMC. They suggest that a combined intervention approach, rather than a single approach, may be most effective in improving family caregiver outcomes and that research is needed to determine which combination of domains are most effective to reduce the burden of care as well as “what works best for whom and when.” They also recommend future studies to measure long-term stress reduction and impacts on family members beyond the maternal caregiver. The authors close by highlighting the importance of larger scale experimental design studies, while recognizing that such studies will be methodologically challenging.

3. Fields, N.L., Anderson, K.A., and Dabelko-Schoeny, H. (2014). The effectiveness of adult day services for older adults: A review of the Literature from 2000 to 2011. *Journal of Applied Gerontology, 33 (2): 130-163.*

Study Aim/Purpose: The aim of the study was to summarize literature from 2000-2011 on Adult Day Services (ADS) effectiveness and make recommendations for future research. The study was intended to update a similar review conducted by Gaugler and Zarit in 2001.

Summary of Methods: The researchers summarized findings from published qualitative and quantitative, peer-reviewed English language studies of ADS effectiveness (i.e. effects on participant, caregiver or health care utilization). Articles were identified through searches of Medline, Ageline, Psychology and Behavioral Sciences Collection, Social Work Abstracts, SOCIndex, and CINAHL, and Google Scholar. The search was conducted with the terms: adult day, adult day services, adult day health care, respite services, community-based care, and community-based long-term care. Multiple reviewers independently assessed the abstracts to determine whether they met the criteria of being studies of effectiveness of ADS.

Summary of Key Results: 61 studies were included in the final literature review sample. Of these 39 related to participant outcomes, 19 related to caregiver outcomes and 10 related to ADS and health care utilization. The authors equate care receiver participation in ADS with receipt of respite by the caregiver. A table listing the methods and findings of each reviewed article is provided in the body of the article. Key findings on caregiver and health utilization outcomes are summarized below:

ADS use and caregiver outcomes: Several studies reviewed demonstrated that ADS attendance and the general benefits provided by ADS (e.g., respite and basic ADS programming) had significant positive effects on caregiver burden and stress. Two reviewed studies found that caregivers who received supplemental caregiver support services along with ADS had significantly higher feelings of competence or increased capacity to manage challenging behaviors than caregivers who only received usual ADS services. Another study of the *Best Friends Approach* to ADS for dementia care (i.e., involving a person-centered philosophy and special staff and volunteer training) found gains in overall quality of life for caregivers.

ADS use and health care utilization: Several studies on timing of nursing home placement had inconsistent results more often showing that ADS programs do not delay nursing home placement. One study of ADS use for individuals with dementia found the association between ADS use and shorter time to nursing home placement was significant for wife caregivers but not for daughter caregivers. The authors conclude that caregivers who used high amounts of ADS may have used these services as a transition or “stepping stone” to institutionalization. Two reviewed small studies examining the effectiveness of supplemental caregiver supports provided with ADS found lower rates of nursing home placement and greater delays in nursing home placement for users of ADS programs providing supplemental caregiver supports than for users of usual ADS programs. One reviewed study of a pilot ADS program that provided acute health services after a participant was discharged from a hospital stay found significant reductions in hospital readmissions among pilot

participants compared to participants who were sent to skilled nursing facilities, home health, or home with outpatient services or self-care after hospital discharge.

Limitations of Studies Reviewed (as cited by the author): They authors indicated that while their literature review was comprehensive, it may have missed several small studies of ADS.

Authors' Discussion/Conclusions: The authors conclude that ADS can benefit caregivers, for example, by reducing their burden and stress. However, they suggest that their review leaves many questions unanswered including: what elements of ADS programming have significant effects; what type of participants and caregivers are helped by ADS; how much ADS usage is needed to have an effect; and the mechanisms through which ADS has effects and under what circumstances. At the same time, the authors point out that measuring the effects of a specific type of ADS program for a specific population is challenging due to the small size of most ADS programs and inter- and intraprogram variability in the services offered.

With regard to research on the effect of ADS on nursing home placement and other health care utilization, the authors recommend future research include: effects of prior ADS use on participants and caregivers after transition to institutional settings; cost effectiveness of ADS programming; and large scale evaluations of ADS programming that have promise for reducing health care costs, such as those that address chronic health conditions.

4. Knapp, M., Lemmi, V., and Romeo, R. (2013). Dementia care costs and outcomes: a systematic review. *Int J Geriatr Psychiatry*, 28: 551-561.

Study Aim/Purpose: The purpose of this article was to review available literature evaluating the cost effectiveness of dementia care prevention, care and treatment strategies.

Summary of Methods: The authors conducted an electronic search for published articles from 2005 and a web search of articles from 2000 onward evaluating interventions for people with dementia or their caregivers, which reported evidence on service use or costs, conducted in high income-countries. The databases searched included PubMed/Medline, Embase, PsychINFO, EconLit, The Cochrane Library, and the Center for Reviews and Dissemination. Additionally the following British Websites were searched: National Institute for Health and Clinical Evidence, the Social Care Institute for Excellence, the National Audit Office, the Royal College of Psychiatrists, the Royal college of General Practitioners, the Alzheimer's Society, the King's Fund, Carers UK, the Mental Health Foundation, Age U and the Bradford Dementia Group. The search included studies written in English, French, Italian and Spanish using a wide range of study designs (e.g., quantitative, qualitative, mixed-methods and economic evaluations). Meta-analysis was not performed because of the heterogeneity of the studies. Narrative analysis was used to synthesize results in four areas: 1) pharmacological interventions; (2) non-pharmacological interventions for individuals with dementia; (3) interventions for carers of individuals with dementia; and (4) organization of care and support.

Summary of Key Results (related to studies of effectiveness): The search identified 56 literature reviews and 29 single studies that included pharmacological and nonpharmacological interventions for persons with dementia as well as respite and other supports for caregivers. With regard to studies on respite and supports for caregivers, the authors found some evidence of the cost effectiveness of respite care when provided in out-of-home day respite programs. However, no economic evidence was found for in-home respite, host family respite, institutional or overnight respite, or video respite. Several reviewed studies also indicate potential cost effectiveness of psychosocial interventions and training programs targeted to caregivers, with savings resulting from either significant delays in nursing home placements or reduced caregiving hours for the family caregiver. The authors indicate that there was also some evidence to suggest that coordinated care management and personal budgets for care provided to and controlled by caregivers could be cost-effective.

Limitations of Studies Reviewed (as cited by the author): The authors note that the quality of the extant literature on economic evaluations of dementia care was low, and none of the findings in the literature reviews summarized were supported by meta-analysis because of the limited amount and heterogeneity of the available studies. For this same reason, the authors were unable to perform a meta-analysis on studies included in their review.

Authors' Discussion/Conclusions: With regard to recommendations for future research in this area, the authors recommend that studies examine cost savings and impacts beyond health costs to measure the economic impacts of dementia and dementia care more broadly including, for example, the opportunity costs of caregiver inputs and the impacts of caring on the health and well-being of caregivers.

5. Lopez-Hartmann, M., Wens, J., Verhoeven, V., and Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers or community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care*, 12: 1-14.

Study Aim/Purpose: The aim of the review was to summarize research on the effectiveness of caregiver interventions targeting informal caregivers of frail elderly living in the community.

Summary of Methods: In September 2010, the authors conducted a systematic search in Medline, sychINFO, Ovid Nursing Database, Cinahl, Embase, Cochrane Central Register of Controlled Trials, and British Nursing Index of reviews and original effectiveness studies published in English, French, German or Dutch. The authors selected a subset of articles based on a methodological quality assessment of the studies using the Scottish Intercollegiate Guidelines Network's methodology checklists.

Summary of Key Results (related to studies of effectiveness): A total of 14 articles (four literature reviews and 10 primary research studies) were included in the review. The authors found that, overall, while the effect of caregiver support interventions is small and inconsistent between studies, there is evidence that respite care can be helpful in reducing depression, burden, and anger. In addition, interventions targeted at the individual caregiver level can be beneficial in reducing or stabilizing depression, burden, stress, and role strain. There is some evidence that group support for caregivers has a positive effect on their coping ability, knowledge, social support, and in reducing depression. Finally, the limited research on technology-based interventions provided evidence that types of interventions can reduce caregiver burden, depression, anxiety and stress and improve caregivers' coping ability.

Limitations of Studies Reviewed (as cited by the author): The authors recognized that their primary search term "frail elderly" might not have captured all relevant articles since the term is a new concept in the literature. They also suggest that their review's focus on quantitative studies should have been broadened to include qualitative studies to examine such topics as how the intervention is experienced by the population it is targeted to serve.

Authors' Discussion/Conclusions: The authors recommend that future research on caregiver support interventions pay attention to the influence of caregivers' characteristics and context on the outcomes. With regard to study design, they suggest that randomized controlled trials might not be the best method for evaluating caregiver support interventions. Instead, they suggest research examining the economic savings of caregiver interventions, and studies using qualitative methods should be considered. They also emphasize the importance of integrated programming that combines multiple supports, such as respite and one-on-one caregiver support services. They also recommend that the intervention be tailored to the individual caregiver's physical, psychological, and social needs and that future research examine the long-term effect of such integrated and tailored caregiver support services.

6. Neville, C., Beattie, E., Fielding, E. and MacAndrew, M. (2015). Literature review: Use of respite by carers of people with dementia. *Health and Social Care in the Community*, 23 (1), 51-63.

Study Aim/Purpose: The review summarizes research findings on factors affecting respite use and outcomes for carers of people with dementia living in the community.

Summary of Methods: The authors conducted a search of English language articles from Australasia, the United States, Canada, United Kingdom, and Europe primarily using EBSCOhost via CIAHL, MEDLINE, and PsycINFO databases with search terms including Alzheimer’s disease, dementia, respite, adult day care, carer and caregiver. The main time period covered was 1990-2012, but a few earlier articles were also included. The search included a wide range of study designs with “all levels of evidence,” including literature reviews/meta-analyses, randomized control trials, quasi-experimental studies, descriptive studies (observational or quantitative surveys), qualitative research, and expert opinion publications.

Summary of Key Results (related to studies of effectiveness): Reviewed studies demonstrated that lack of knowledge of the availability of respite is a major contributor to its poor usage. The literature suggests the following additional factors affecting respite use: the carer’s perception of need for respite; whether the caregiver felt duty bound to providing care; whether respite was perceived as able to help the person with dementia; family or societal stigma against use of respite; concerns about quality of care; and the accessibility of suitable or dementia-specific respite services. Reviewed qualitative studies suggested that spouses may feel a greater sense of duty than other family caregivers and so may tend to be more reluctant to use respite.

The review found conflicting evidence regarding significant effects of respite on carer physical or mental health, anger and depression, stress, burden (beyond the short term period when respite is being used), and general quality of life. The studies analyzed also demonstrated limited if any consistent positive or adverse effects of respite use on the health of persons with dementia (e.g., on their cognition, function or physical health) or on delaying their placement in a residential facility. Studies also indicated that that outcomes of respite care for any individual caregiver are affected by his/her satisfaction with the care, and how the carer spends his/her respite time is an important variable impacting their satisfaction.

Limitations of Studies Reviewed (as cited by the author): The authors suggest that using the word ‘respite’ in their literature search may have resulted in missing some important articles that evaluated respite-like services, but did not use the term.

Authors’ Discussion/Conclusions: The authors conclude by suggesting future research on respite include a sufficiently large and diverse sample size to enable the exploration of the factors affecting respite use, carers’ satisfaction or dissatisfaction with the service, its impact on carers and care recipients as well as the influence of diverse background characteristics and external factors on these impacts.

7. Tretteteig, S., Vatne, S. and Rokstad, A.M.M. (2016). The influence of day care centers for people with dementia on family caregivers: An integrative review of the literature. *Aging & Mental Health*, 20(5): 450-462.

Study Aim/Purpose: The aim of the study was to summarize and analyze existing research on the influence of adult day care centers (DCCs) for people with dementia on family caregivers.

Summary of Methods: The review used an integrative review framework to summarize findings of peer-reviewed published qualitative and quantitative studies located through searches of Pub Med, the Norwegian Electronic Health Library – Full Text, AMED (1985-2013), Embase (1996-2013), Ovid MEDLINER (1996-2013) and PaycINFO (1987-2013). The search was conducted with the following terms: relatives/next of kin/family-carer/informal carer and day-care/day-care-center and dementia. Only studies that included the family caregiver and described their needs, their experiences and/or the effects of DCCs on persons with dementia were included. Quality of the papers was assessed by a mixed methods appraisal tool.

Summary of Key Results (related to studies of effectiveness): A total of 19 studies was included in the final literature review sample. Of these, two were solely qualitative, 15 were quantitative (8 using randomized controls), and two used mixed-methods designs. Qualitative and mixed methods studies reviewed found that caregivers (more so women than men) want a DCC that improves their competence in caring for the care recipient, cares well for the person with dementia, and makes the caregiver feel there is shared responsibility for their loved one. Studies examining the effects of DCC on caregiver burden found that DCC use can reduce caregiver burden, but findings were mixed, with a larger decline in feelings of overload among daughters and daughters-in-law than for wives. Several studies reviewed found use of DCCs with good caregiver support was associated with increased motivation for the caregiver role and postponement or prevention of institutional placement. Finally, the research also pointed to two mediating factors affecting respite use and thus its outcomes: (1) the gender of the carer and relationship of the caregiver to the care recipient (child or spouse); and (2) the level of impairment of the person with dementia. For example, one study found that family caregivers of a person with dementia who dropped out of a DCC after a few months had significantly higher values of worry, overload, and role captivity than those who remained in the program.

Limitations of Studies Reviewed (as cited by the author): The authors noted that many of the studies reviewed had small sample sizes. Further, they stressed that while numerous studies examine the outcomes of DCCs, there has been no standardized definition of content or quality of DCC services across studies or how these programs are tailored to meet individuals' needs.

Authors' Discussion/Conclusions: While their review indicates that DCCs have the potential to provide much needed respite and support service for family caregivers, the authors recommend that future research and practice in the respite field place an increased focus on both the provision of respite time and caregiver support, taking the diversity of family caregivers' and care recipients' needs into consideration.

8. Vandepitte, S.V., Noortgate, N.V.D., Putman, K., Verhaeghe, S., Verdonck, C. and Annemans, L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: A systematic review. *Int J Geriatr Psychiatry*, 31: 1277-1288.

Study Aim/Purpose: This study was designed as a systematic review of studies on the impact of respite care for caregivers of persons with dementia.

Summary of Methods: The authors conducted a systematic search of articles published since 2000 on the effect of respite care on caregivers, care recipients or health care resource use, where the caregivers are informal and the care recipients had been diagnosed with dementia and live primarily at home. The search was conducted using PubMed and Web of Science and included studies written in English, German, Dutch, and French. Only studies using experimental design studies (with RCTs), quasi-experimental design with comparison groups, pre/post intervention outcome studies without a control group, and cohort studies were included. The studies were also evaluated to be of strong, medium or weak methodological quality, using the Quality Assessment Tool for Quantitative Studies.

Summary of Key Results (related to studies of effectiveness): The authors identified 17 studies for review, with varying levels of quality. A summary of key findings is grouped below by respite care type.

Out-of-home day care respite. Six of the eight day care program studies indicated improvement in caregiver burden and stress related outcomes. Six of the seven day care program studies indicated decreased behavioral problems and possibly improved sleep quality for care recipients. Two studies found that respite day care alone actually accelerated time to nursing home placement for persons with dementia. At the same time, one methodologically strong study comparing receipt of adult day care integrated with support and information services to a control receiving only day care found significant impact on care recipient behavioral problems and an increased delay in nursing home placement for the individuals who received the integrated programming.

Temporary residential admission. One study found a positive effect of temporary residential respite on caregiver sleep quality during the temporary respite period. No other impacts on caregivers or strong positive impacts on care recipients were found.

In-home respite. The review found only one study of in-home respite for persons with dementia and rated it as having weak methodological quality.

Limitations of Studies Reviewed (as cited by the author): The authors note that the comparability of respite studies is limited because various types of respite services are often poorly described and vary in terms of the lengths of respite offered; the respite studied is used for varying reasons; and, the studies use different outcome measures.

Authors' Discussion/Conclusions: They authors recommend that more research be conducted to enable the measurement of impact of a specific model of respite care, especially in the area of in-home respite care. And, these studies should look at outcomes at three levels: the caregiver, the care recipient, and health care resource utilization.

9. Whitmore, K.E. (2016). Respite care and stress among caregivers of children with autism spectrum disorder: an integrative review. *J Pediatr Nurs*, 31(6):630-652.

Study Aim/Purpose: The aim of this paper was to review existing primary research studies examining the relationship between respite care and stress among caregivers of children with autism spectrum disorder (ASD).

Summary of Methods: The review used an integrative review framework to identify English language studies published within the last 10 years that used either experimental or non-experimental designs. Articles were located using the PubMed, CINAHL, ERIC, and Psych Info databases using the following key words: ‘child development disorders pervasive’ or ‘autism’ or ‘autism spectrum disorder’ and ‘stress’ or ‘parent stress’ or ‘caregiver stress’ and ‘respite care.’ Additionally, references from articles identified in the database searches were reviewed to identify additional articles for inclusion.

Summary of Key Results (related to studies of effectiveness): A total of 26 documents was identified and a final sample of 11 articles were included in the review. Of these, ten were appraised as descriptive or qualitative studies and one was an expert opinion publication. While most of the studies found that respite care was associated with lower stress, several found that respite care was associated with higher stress, and one found no association.

Limitations of Studies Reviewed (as cited by the author): The author found that the quality and scientific rigor of studies reviewed were limited. The studies were all descriptive, observational studies using retrospective design with no control groups. The author also noted limited comparability across studies because study sample size (ranging from six to 166) and measures of respite care and caregiver stress varied greatly. The author also pointed out the homogeneity of the study populations with the majority only studying caregivers who were Caucasian females, well-educated, married or partnered, not poor, and employed at least part-time.

Authors’ Discussion/Conclusions: The author states that “due to the lack of consistency and quality across the studies,” findings must be interpreted with caution and “significant gaps remain.” A model for future research is proposed that takes into account intermediate factors such as (1) the adequacy of informal respite care (e.g., provided by family members, friends, neighbors, and faith-based organizations); (2) the effects of informal respite care on caregivers’ stress level and their need for formal respite care; and (3) the adequacy of the formal respite care received (e.g., using measures of frequency, duration, and timing as well as caregiver satisfaction with respite care). The author also recommends that research be conducted with more demographically diverse populations of caregivers including non-White mothers, fathers, caregivers living in rural areas, and caregivers with lower incomes and educational levels.

Added in 2020

- 1. Ellen, M.E., Demaio, P., Lange, A., and Wilson, M.G. (2017). Adult day center programs and their associated outcomes on clients, caregivers, and the health system: a scoping review. *Gerontologist*, 57 (6): e85-e94.**

Study Aim/Purpose: The purpose of this paper was to summarize findings and identify gaps in the literature evaluating outcomes of stand-alone adult day center (ADC) programs serving older adults in the community.

Summary of Methods: The authors conducted a scoping review of evaluations of standalone ADCs published in English from 2004 through October 2014 searching Medline, Embase, CINAHL, PsychINFO, and AgeLine (Supplementary File I). Search terms used were “senior” and derivatives such as “older adult”, “elder” or “aged,” and “respite care” or “day care” and derivatives. Using these search terms and inclusion criteria, authors identified 76 studies. Study population characteristics, methods, outcomes measured, and findings were extracted and coded. Coded extracts were mapped by type of outcome assessed, the study population, disease focus, service focus and healthy system considerations.

Summary of Results: The authors note that the majority of studies on standalone ADC focus on older adults with dementia, and that the majority of these studies focus on outcomes related to respite for caregivers. At the same time, studies of ADCs and the non-dementia population were more likely than studies of the dementia population to assess the implementation components of the ADCs, including health promotion and screening, and strategies such as information, education, competencies development and facilitation of decision-making. Across populations studied, the authors found a substantial amount of literature showing that ADC use has positive health, social, and psychological and behavioral outcomes for both care recipients and caregivers. In contrast, the authors found limited research on the accessibility of ADC care or its cost-effectiveness and system outcomes. Additionally, they report ambiguous findings in the studies examining ADC as a deterrent to long-term care placement, social isolation and further cognitive decline.

Study Limitations (as cited by authors): The authors cited the following limitations of their review, noting that some limitations are common in scoping reviews: 1) the review excluded research not published in peer-reviewed journals; 2) none of the identified studies were conducted in lower-middle-income countries; 3) the study outcomes are not necessarily attributable to only use of ADCs; and 4) the coding was conducted by only one researcher, limiting the reliability of the results.

Authors’ Discussion/Conclusions: The authors suggest that more in-depth analysis of ADC outcomes is needed through systematic reviews that empirically assess the effects of different ADC models on older adults and their caregivers. They also recommend that future research differentiate the outcomes of ADCs based on the population served, the programming provided, and how the services are used. This research, they suggest, could translate into processes and mechanisms that would identify the individual needs of older adults and their families and provide access to the appropriate kinds of providers and programs for their needs.

2. Maffioletti, V.L.R., Baptista, M.A.T., Santos, R.L., Rodrigues, V. M., Dourado, M.C.N. (2019). Effectiveness of day care in supporting family caregivers of people with dementia: A systematic review. *Dement Neuropsychol*, 13(3): 268–283.

Study Aim/Purpose: The purpose of this paper was to summarize literature on the strategies used in day care for supporting family caregivers of people with dementia, as well as their effects on family caregiver burden, coping strategies, and quality of life.

Summary of Methods: The authors conducted a systematic review of literature published in English or Portuguese from 1998 to 2017. The search was performed using PubMed, PsycInfo, Scopus and SciELO databases with search keywords: “day care” or “care day” or “partial hospitalization”; “dementia” or “Alzheimer disease” or “Alzheimer’s disease” or “Alzheimer type dementia”; “caregiver” or “family caregiver” or “carers”; and “quality of life” or health related quality of life”; and “adaptation, psychological” or “coping behavior” or “coping skills.” The authors included cross-sectional or longitudinal descriptive studies; evaluation studies using randomized or non-randomized designs, including both those with and without control groups; and other studies of caregiver outcomes of day care for people with dementia. Exclusion criteria were used as well, such as studies focused on the outcomes for persons with dementia. The authors also screened titles for inclusion based on a rating of the quality of their research methods using the *Mixed Methods Assessment* tool. After review by all the authors, 21 papers were included. Ten of the 21 studies were conducted in the USA, three in the Netherlands, one in Norway, one in Norway and Scotland, one in Iceland, one in Hong Kong, one in Australia, one in Italy, one in Sweden and one in Germany. No randomized controlled trials were found.

Summary of Results: The authors found great heterogeneity in the structure and organization, intervention strategies, and theoretical bases of the day care programs studied. At the same time, 10 of the 21 studies did not fully describe the activities offered, which the authors attributed to the fact that the studies focused on investigating the benefit of the break from care for the family caregiver rather than the content of the services provided to the patient. Where it could be determined, some programs studied offered activities only for the person with dementia, while others offered activities for the dyad. Where behavioral improvements were identified, this was also associated with reduced burden for family caregivers. Integrated programs providing activities for the dyad found increased feelings of competence and self-confidence of family caregivers, allowing them to postpone institutionalization.

Study Limitations (as cited by authors): The authors cautioned that the heterogeneity of the day care programs’ structure and organization, design and theoretical basis, and the size of the study samples hinders cross-study comparison. They also highlighted the variation in assessment methodologies used across studies. For example, some studies compared outcomes on days with day care treatment to the days when the person with dementia was cared for at home; others compared outcomes of family caregivers using day care to non-users, while others only interviewed the family caregivers of day care users.

Authors’ Discussion/Conclusions: The authors conclude that despite the great diversity of methods, samples, measuring instruments and interviews, most of the studies reported similar positive results in

reducing family caregiver burden, thus use of day care for persons with dementia appears to be promising for improving the health and quality of life for their family caregivers. Their findings suggest that programs serving both the patient and family caregiver offer a more promising approach than those that only serve the patient, and that they have potential to promote health, prevent disease, and minimize burden and enable long-term care in non-institutional settings. At the same time, the authors cautioned that the conception of day care as only a respite service for the benefit of the caregiver restricts the understanding and evaluation of its role as a treatment and rehabilitation service for persons with dementia as well as a source of guidance and support for their family caregivers.

3. Walter, E., and Pinquart, M. (2019). How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. *The Gerontologist*, Advance Access publication September 17, 2019.

Study Aim/Purpose: The purpose of this paper was to update a 2006 meta-analysis of interventions for caregivers of persons with dementia that was conducted by Pinquart and Sorensen. The analysis sought to determine the average effects of interventions for caregivers of individuals with dementia on caregivers and their care recipients, how these effects differ between intervention types, and the impact of study characteristics, caregiver characteristics, and the relationship between the caregiver and care recipient on these effects.

Summary of Methods: The authors conducted a systematic review of literature published in English, German, or a language for which they could obtain translation, published after the 2006 meta-analysis. The search was performed using PubMed, PsychINFO, and PSCYINDEX, using the search terms: 1) “dementia” or “Alzheimer’s disease” and 2) “caregiver” or “carer” or “caregiving” and 3) “intervention” or “trial” or “support” or “training”, and 4) “control” or “controlled” or “RCT” or “experiment” or “experimental.” The inclusion criteria for studies were: care receiver has dementia, participants are informal caregivers (relatives or friends), the intervention is psychosocial, there is a treatment and control group with assignment implemented in a way that should not lead to systematic differences between groups, and at least one of the desired outcomes was reported to allow for computation of effect size. After review by the authors, 280 studies were included. The intervention types were categorized according to their dominant component in 7 categories: psychoeducational, cognitive-behavioral therapy, counseling/case management, general support, respite, training of the care receiver (e.g. memory training), and multicomponent interventions. The outcome measures that we included in the analysis were: caregiver burden, depression, subjective well-being, ability and knowledge, anxiety, and symptoms of the care receiver with dementia.

Summary of Results: Caregiver interventions had, on average, significant small-to-moderate effects on improvement of the caregiver’s ability/knowledge, subjective well-being, burden, depression, and anxiety as well as on symptoms of the care recipient. Younger male and non-spouse caregivers appear to be more likely to have reduced burden and depression, whereas women are more likely to have gains in ability/knowledge. Examining the outcomes by intervention type demonstrated that multi-component skill-building psychoeducational and cognitive-behavior therapy interventions affected most outcomes; whereas the effects of other intervention types were limited to specific outcomes. Only multicomponent interventions were found to be effective in reducing the risk of institutionalization at post-test.

Study Limitations (as cited by authors): The authors noted several limitations of the meta-analysis. First, despite the relatively large number of studies included, the test power was limited for testing the mostly small intervention effects. They also explained that the classification of interventions was ambiguous at times because an intervention that is primarily of one type may also use principles from another type or have a small component of another type. This overlap in intervention type may explain why there was similar mean effect size on burden and depression for skill-building, psycho-educational, cognitive-behavioral therapy, and counseling/case management interventions.

Authors' Discussion/Conclusions: With regard to programmatic application of the study findings, the authors recommend that practitioners of programs serving caregivers choose interventions based on whether broad or specific outcomes are desired. Because interventions that were purely informational had no effect on most outcomes, they also recommend that interventions include some form of active participation or training. With regard to future research, the authors conclude that more primary research is needed on the effects of respite and support interventions as well as on training of the care recipient and the long-term effects of caregiver interventions. Additionally, they suggest that future quantitative syntheses of studies examine the effects of individual components or different combinations of components among multi-component interventions. Finally, they recommend that, as with other therapy research, more research is needed to understand the processes and change mechanisms by which dementia caregiver interventions realize their effects.

VII. Methodological Issues in Research on Respite and Caregiver Interventions

Added in 2018

1. Zarit, S.H. (2017). Past is prologue: How to advance caregiver interventions. *Aging & Mental Health, 10*: 1-5.

Study Aim/Purpose: This article is a retrospective overview of research on caregiver interventions to highlight strengths and weaknesses and identify conceptual and methodological issues that could lead to better treatment outcomes.

Summary of Methods: The author provided a critical review of the literature of caregiver interventions, drawing examples from studies of psychosocial interventions for caregivers of persons with dementia; however, the issues raised are considered relevant to interventions for caregivers of persons with other types of health issues. The paper also briefly addresses research on respite care.

Summary of Results: The paper critiques the literature on caregiver treatment interventions and explains the limited positive outcomes as a result of the lack of consideration of differences in symptoms and needs among caregivers in the pre/post analysis of change in outcomes. For example, in most caregiver intervention studies the main outcome is depressive symptoms and studies have typically found only modest changes in this outcome. Researchers, the author notes, have partly addressed this issue by including measures of other outcomes, such as subjective burden, stress, and aspects of health and quality of life; however, treatment effects on these outcomes have also been limited. The author also found that the potential measurable impact of interventions are diluted because they generally use a “one-size fits all” treatment approach that may not address the problems that individual caregivers have or the outcomes they are looking for. He goes on to suggest that focusing on problems that caregivers do not have could also not only dilute positive outcomes but “could under some conditions lead to adverse outcomes.”

Authors’ Discussion/Conclusions: The author’s major recommendations were the following: (1) Engage caregivers in discussions of what they need, including using qualitative research methods; (2) Design interventions with adaptive approaches that consider the heterogeneity of the caregiving population and allow tailoring and sequencing of intervention components based on individualized assessment of caregivers’ needs; (3) Use process measures to determine fidelity of intervention implementation; (4) Design evaluations with a sample size adequately powered to detect differences in subgroup effects (e.g., variation based on caregivers’ baseline stress levels); and (5) Test the mechanisms by which treatment leads to improved outcomes (e.g., determining if individual treatment components have their intended short term effects; the links between intermediate outcomes like coping and longer-term outcomes such as reduced distress post-treatment and beyond).

2. Zarit, S., Bangerter, L., Liu, U., and Rovine, M.J. (2017). Exploring the benefits of respite services to family caregivers: methodological issues and current findings. *Aging & Mental Health*, 21 (3): 224-231.

Study Aim/Purpose: This literature review focuses on methodological issues that have impeded reliable and valid research studies involving respite care. There is special emphasis on how these methodological issues affect conducting research and practice settings, and how these issues may limit, or in some cases should limit the research designs available to conduct outcome studies. The authors list a number of suggestions about how these issues may be addressed or resolved.

Summary of Key Findings: Drawing examples primarily from published work on out-of-home adult day services and its impact on family caregivers, the authors discuss several challenges to the validity of randomized controlled trials (RCT) research on respite including: the usual small sample size of respite studies; differential attrition between the treatment and control groups; and inadequate implementation of the respite service (e.g., offering a too low level of respite to have an effect). The authors also suggest that the inability to measure change in outcomes may be because the caregivers being studied either begin respite early and thus have low levels of stress and burden at study baseline or because the caregivers of both groups have very high levels of stress and thus over time there will likely be regression to the mean, obscuring differences between the groups due to respite use. They also suggest that the outcomes now being measured be examined to focus on those most reasonable to expect of respite and to consider selecting outcomes based on caregivers' goals.

The authors lay out several alternative research designs and recommend using a quasi-experimental treatment/control design. They recommend that the potential negative effects of not randomizing control and treatment groups be addressed in several ways, including (1) selecting a control sample from a different setting or community where the treatment is not available; and (2) matching for and adjusting for covariates such as caregiver and care recipient characteristics, their propensity to use respite, and baseline measures for key outcomes associated with respite use. The authors also recommend the use of a quasi-experimental design they call "removed treatment and reversal" that measures and compares caregivers' outcomes on the days they use respite to the days they don't use respite. The authors also recommend the use of interrupted time-series designs when identifying or constructing a control or comparison group is not possible.

Authors' Discussion/Conclusions: The authors conclude that reliance on RCTs restricts the range of research that can be conducted in community settings and limits the testing of innovative models of change that could lead to more effective individualized treatment approaches for respite as well as for many other community interventions. In addition to recommending the use of quasi-experimental design in future research, they also suggest that multiple types of outcome/impact measures be used, including self-reports, observations and biological measures.

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