

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM'S RESPITE SERVICES AND THE EFFECT ON THE CAREGIVING EXPERIENCE

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ABSTRACT

This study uses data from the National Family Caregiver Support Program portion of the National Survey of Older Americans Act Participants (n= ~4,800) to explore the relationship between respite care and caregiver burden. The study found that participants of respite care were significantly more likely to report that they had more time for personal activities, found it easier to care for the care recipient, and felt less stress as a result of receiving respite care services. These results are consistent with some literature; however, there are some studies that do not support the positive effects of respite care. Studies have linked these mixed results with deterrence from using respite care, and therefore more research is needed in order to appropriately meet the needs of caregivers. Although this study found that respite care led to positive and significant outcomes for caregivers, previous studies have not found that respite care yields positive outcomes for caregivers. These mixed results on the value of respite care may be due an inconsistency in the definition of respite care across programs and states, and the inconsistency of the respite services themselves.

This paper aims to explore the relationship between the use of respite services provided by the National Family Caregiver Support Program (NFCSP) and caregiver experiences. As the United States' 65 and older population continues to grow by about 2.3% each year, the need for caregivers will continue to grow¹. Because respite care is one of the most commonly requested services by caregivers², it is important to understand the impact and effectiveness of these services. Using the 2011-2013 results of the National Survey of Older Americans Act Participants, three logistic regressions will be used to identify the relationship between NFCSP respite services, and perceived time caregivers have for personal activities, the ease of caregiving, and level of caregiver stress.

BACKGROUND

Caregiver Burden

In 2013, there were an estimated 40 million family caregivers in the United States³. These caregivers provided an estimated 37 billion hours of care in various care recipient scenarios such as cancer, dementia, heart failure, transitions in care, and stroke⁴. Caregivers not only perform tasks such as bathing, shopping, and managing finances, but often perform medical and nursing tasks such as wound care and medication management⁵. The stress of caring for these types of recipients have, in many instances, led to negative health effects and financial burdens for the caregiver⁶.

The term “caregiver burden” is often identified in literature as the “overwhelming responsibility of caregivers”⁷. In “Home Alone: Family Caregivers Providing Complex Chronic Care”, researchers Reinhard, Levine, and Samis found that the more medical and nursing tasks a

1 Divison of Population Health. Caregiving. December 7, 2010. <http://www.cdc.gov/aging/caregiving/>.

2 Reinhard, Susan C. , Lynn Friss Feinberg, Rita Choula, and Ari Houser. Valuing the Invaluable: 2015 Update. Washington, D.C.: AARP Public Policy Institute, 2015.

3 Ibid.

4 Ibid.

5 Reinhard, Susan C., Carol Levine, and Sarah Samis . Home Alone: Family Caregivers Providing Complex Chronic Care. Washington, D.C.: AARP Public Policy Institute, 2012.

6 Collins, Lauren G., and Kristine Swartz. “Caregiver Care.” *American Family Physician* 83, no. 11 (2011): 1309-1317.

7 Cangelosi, Pamela R. “Caregiver BURDEN or Caregiver GAIN? Respite for Family Caregivers.” *Journal of Psychosocial Nursing* 47, no. 9 (2009): 19-22.

caregiver performed, the higher the caregiver's levels of depression and anxiety, including feeling the need to constantly watch out for something to go wrong, feeling stress about talking to medical professionals, and feeling worried about making a mistake⁸. In addition, Cangelosi found that caregivers report higher rates of heart disease, arthritis, and diabetes, and that depression, sleep disorders, and even death have been linked with the strain of caregiving⁹.

Respite Care

Respite care is meant to address one of the most important needs of a caregiver: temporary relief¹⁰. The Older American Act defines respite care as time when caregivers can be "temporarily relieved from their caregiving responsibilities."¹¹ van Exel, de Graaf and Brouwer observed three types of caregivers: those who needed respite care and asked for it, those who needed respite care and did not ask for it, and those who did not need respite care¹². The caregivers who needed respite care experienced caregiver burden. Cangelosi notes, however, that caregivers often do not seek respite care until they are physically or emotionally depleted¹³.

Several studies have addressed factors influencing respite care use. Brown, Freidmann, and Mauro, for example, found that even though half of a low-income population perceived the need for adult daycare (a type of respite care service), only 19.1% used the service¹⁴. The use was mostly when care recipients had severe cognitive impairment¹⁵.

- 8 Reinhard, Susan C., Carol Levine, and Sarah Samis . Home Alone: Family Caregivers Providing Complex Chronic Care. Washington, D.C.: AARP Public Policy Institute, 2012.
- 9 Cangelosi, Pamela R. "Caregiver BURDEN or Caregiver GAIN? Respite for Family Caregivers." *Journal of Psychosocial Nursing* 47, no. 9 (2009): 19-22.
- 10 Reinhard, Susan C. , Lynn Friss Feinberg, Rita Choula, and Ari Houser. Valuing the Invaluable: 2015 Update. Washington, D.C.: AARP Public Policy Institute, 2015.
- 11 Houser, Ari, and Kathleen Ujvari . The State of Measurement of Respite Care. Washington, D.C. : AARP Public Policy Institute, 2012.
- 12 van Exel, Job, Gjalte de Graaf, and Werner Brouwer. "Care for a break? An investigation of informal caregivers' attitudes toward respite care using Q-methodology." *Health Policy* 83 (2007): 332-342.
- 13 Cangelosi, Pamela R. "Caregiver BURDEN or Caregiver GAIN? Respite for Family Caregivers." *Journal of Psychosocial Nursing* 47, no. 9 (2009): 19-22.
- 14 Brown, Ellen L., Marie-Luise Friedemann, and Ana C. Mauro. "Use of Adult Day Care Service Centers in an Ethnically Diverse Sample of Older Adults." *Journal of Applied Gerontology* 33, no. 2 (2014): 189-206.
- 15 Ibid.

Some researchers attribute nonuse of respite care to caregiver related factors. Casado, for example, found that sense of need for respite care and financial support were related to race and ethnicity, relationship with care recipient, financial status, availability of substitute help, family agreement, caregiving hours, interpersonal burden, and personal burden¹⁶. van Exel, de Graaf, and Brouwer attributed attitudes towards respite care to the caregiver's education level, employment status, health and happiness, gender of recipient, duration and intensity of caregiving, relationship, co-residence, need for surveillance, and subjective burden¹⁷. Dal Santo, Scharlach, Nielson, and Fox similarly found that caregivers who use respite care had more demanding care situations than those who did not use the services¹⁸.

In contrast, Menise and Steffen found that relationship type, household income, behavioral dysfunction functional impairment, and caregiver depression were not associated with respite care use¹⁹. In the use of in-home respite care through NFCSP, they found that a major predictor of respite care use among caregivers was previous use²⁰. This is consistent with the findings of Phillipson and Jones who found that caregivers for people with dementia who used day centers for respite care held a more positive view of day centers than nonusers who perceived negative outcomes for care recipients²¹.

Several researchers have found intrapersonal conflict as a reason why caregivers do not seek respite care. According to Cangelosi, caregivers do not seek respite care because they feel loss of control, sadness, sense of failure, and guilt if respite care is needed²². One study found that spouses

- 16 Casado, Bangwa Lee. "Sense of Need for Financial Support and Respite Services among Informal Caregivers of Older Americans." *Journal of Human Behavior in the Social Environment* 18, no. 3 (2008): 269-287.
- 17 van Exel , Job, Gjalte de Graaf, and Werner Brouwer. "Give me a break! Informal caregiver attitudes towards respite care." *Health Policy* 88 (2008): 73-87.
- 18 Dal Santo, Teresa S., Andrew E. Scharlach, Jill Nielsen, and Patrick J. Fox. "A Stress Process Model of Family Caregiver Service Utilization: Factors Associated with Respite and Counseling Service Use." *Journal of Gerontological Social Work* 49, no. 4 (2007): 29-49.
- 19 Mensie, Lauren C. , and Ann M. Steffen. "Predicting In-Home Respite Utilization by Family Caregivers of Older Adults: Results of a Community Study." *Home Health Care Management & Practice* 23, no. 2 (2011): 109-117.
- 20 Ibid.
- 21 Phillipson, Lyn, and Sandra C. Jones. "Use of Day Centers for Respite by Help-Seeking Caregivers of Individuals with Dementia." *Journal of Gerontological Nursing* 38, no. 4 (2012): 24-34.
- 22 Cangelosi, Pamela R. "Caregiver BURDEN or Caregiver GAIN? Respite for Fam-

often felt guilt about leaving spouses with residential respite care, and without continuous communication and updates, caregivers did not make use of the respite care²³. Another study found that caregivers were torn between the need for a break and their anxieties about the impact of in-hospital respite care on a person with dementia²⁴.

Finally, Cangelosi found that conflicting reports on the effects of respite care has also deterred some caregivers from using respite care services²⁵. On the one hand there are some studies that have found that respite care is useful^{26,27,28} but on the other hand, there is no consensus among studies that respite care significantly benefits caregivers and care recipients.^{29,30}

Two reviews of research on respite care found inconclusive results of the benefits on caregivers and care recipients. Maayan, Soares-Weiser, and Lee reviewed four studies on respite care for people with dementia³¹. Their review found that there was no evidence of any benefit of respite care for people with dementia or their caregivers for any outcome such as rates of institutionalization and caregiver burden. These researchers noted, however, that there were many methodological problems with the trials they reviewed including that the trials were small and had short durations. They concluded that more research is needed to understand

ily Caregivers.” *Journal of Psychosocial Nursing* 47, no. 9 (2009): 19-22.

- 23 Berglund, Anna-Lena, and Inger Johansson. “Family caregivers’ daily life caring for a spouse and utilizing respite care in the community.” *Nursing Science* 32, no. 1 (2012): 30-34.
- 24 Gilmour, Jean A. “Dis/integrated care: family caregivers and in-hospital respite care.” *Journal of Advanced Nursing* 39, no. 6 (2002): 546-553.
- 25 Cangelosi, Pamela R. “Caregiver BURDEN or Caregiver GAIN? Respite for Family Caregivers.” *Journal of Psychosocial Nursing* 47, no. 9 (2009): 19-22.
- 26 Stanberry-Beall, Jenny Kay. *Building a Case for Lifespan Respite: The Effects of Formal Respite Care on Caregivers of Family Members with Chronic Dependencies*. Ann Arbor: ProQuest Information and Learning Company, 2006.
- 27 Greenwood, Nan, Ruth Habibi, and Ann Mackenzie. “Respite: carers’ experiences and perceptions of respite at home.” *BMC Geriatrics* 12, no. 42 (2012): 1-12.
- 28 Menise, Lauren C., and Ann M. Steffen. “Depressive Symptoms and Use of Home-Based Respite Time in Family Caregivers.” *Home Health Care Services Quarterly* 29, no. 3 (2010): 120-137.
- 29 Mason, Anne, et al. “The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People.” *Progress in Geriatrics* 55, no. 2 (2007): 290-299.
- 30 Maayan, Nicola, Karla Soares-Weise, and Helen Lee. *Respite care for people with dementia and their carers*. Oxford: The Cochrane Collaboration, 2014.
- 31 Ibid.

the effects of respite care. Mason, et. al also concluded that more “better-quality up-to-date” evidence is needed, attributing their urgent call to the increasingly aging population³². Their 22-study review of the effectiveness and cost-effectiveness of different models of community based respite care, found that effects of all types of respite on caregivers were generally small but positive. They also found that many studies reported high levels of caregiver satisfaction and found no evidence that respite care delays residential care or negatively affects older adults.

National Family Caregiver Support Program

The main sources of publicly funded respite care are Medicaid, state-funded services, and the National Family Caregiver Support Program (NFCSP), which is administered by the Administration on Aging³³. This study will focus on NFCSP, the first federally funded program to formally recognize caregivers³⁴.

Established in 2000 by the Older Americans Act, this program provides grants to states and territories to fund support services for family and informal caregivers, so that they may keep their loved ones at home for as long as possible³⁵. In order to be eligible for NFCSP services, family or informal caregivers must be an adult providing care for an individual at least 60 years of age or individual of any age with Alzheimer’s, or an adult (nonparent) 55+ caring for children under 18 or adults with disabilities³⁶. The services these recipients receive vary from state to state.

Several studies have explored the variations in state programs and implementation. Feinberg and Newman found in case studies conducted on 10 states (Alabama, California, Florida, Hawaii, Indiana, Iowa, Maine, Pennsylvania, Texas and Washington) that states varied greatly in program design and integration of caregiver support into their home and community based care system³⁷. A few years later, these researchers

32 Mason, Anne, et al. “The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People.” *Progress in Geriatrics* 55, no. 2 (2007): 290-299.

33 Houser, Ari, and Kathleen Ujvari . *The State of Measurement of Respite Care*. Washington, D.C. : AARP Public Policy Institute, 2012.

34 Collins, Lauren G., and Kristine Swartz. “Caregiver Care.” *American Family Physician* 83, no. 11 (2011): 1309-1317.

35 U.S. Administration on Aging. *National Family Caregiver Support Program* . n.d. http://www.aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/.

36 Houser, Ari, and Kathleen Ujvari . *The State of Measurement of Respite Care*. Washington, D.C. : AARP Public Policy Institute, 2012.

37 Feinberg, Lyn Friss, and Sandra L. Newman. “Preliminary Experiences of the

examined a nationwide survey of all 50 states and DC since the passage of NFCSP³⁸. They observed severe unevenness in services and service options provided within the states. They also found inconsistencies with eligibility and assessment, service and access, consumer direction, and system development.

Prior to NFCSP, 18 states and DC did not have a state program that supported family or informal caregivers, funded primarily through state general funds. Of the 32 states that had these programs prior to NFCSP, the service components only indirectly helped family caregivers³⁹. This could explain some of the variation in state programs. According to another study, having caregiver support programs funded prior to NFCSP is linked to successful implementation in delivering counseling, support group and training services⁴⁰.

METHODS

Data Source

The pooled cross-sectional data used for this study comes from the National Survey of Older Americans Act Participants from 2011 to 2013. In the first stage, surveyors selected a random sample of Area Agencies on Aging (AAA), and in the second stage, a random sample of clients for each sampled AAA was selected. Phone interviews of this sample were then conducted. The survey covers six services: Home Delivered Meals, Homemaker Services, Transportation, the Family Caregiver Support Program, Congregate Meals, and Case Management. However, this study will only focus on the Family Caregiver Support Program. The sample size for this study is about 4,800 and consists of individuals who have participated in their state's Family Caregiver Support Program.

One major limitation to using the data provided by the National Survey of Older Americans Act Participants is that despite variations in each state's Family Caregivers Support Program, this survey does not collect data on which states respondents are from. These variations in services, and potentially variation in quality could impact the outcome variables but cannot be controlled.

States in Implementing the National Family Caregiver Support Program." *Journal of Aging & Social Policy* 18, no. 3-4 (2006): 95-113.

38 Ibid.

39 Ibid.

40 Giunta, Nancy. "The National Family Caregiver Support Program: A Multivariate Examination of State-Level Implementation." *Journal of Aging & Social Policy* 22, no. 3 (2010): 249-266.

Variables

TABLE 1. DESCRIPTIVE STATISTICS

	Variable	Mean	Std. Dev.	Min	Max
Outcome Variables	More Time	0.66068	0.473519	0	1
	Easier	0.846833	0.36018	0	1
	Stress	0.754756	0.430269	0	1
Independent Variables	Respite	0.599246	0.490093	0	1
	Care Index	44.10107	14.2681	8	60
	Other Services	0.806512	0.395066	0	1
	Income	0.244736	0.42997	0	1
	# Caring for	0.348182	0.881093	0	8
	Left Alone	0.18343	0.387052	0	1
	Caregiver Disability	0.444559	0.496959	0	1
	Year	2012.038	0.818764	2011	2013

This study will analyze three outcome variables to estimate the impact of respite care on caregivers. Each outcome variable is a dichotomous variable (“yes” =1, “no” =0). The first outcome variable “More Time” answers the survey question: “As a result of the caregiver services you have received, do you have more time for personal activities?” As seen in table 1, 66% of respondents answered “yes”. The second outcome variable “Easier”, answers the question: “As a result of the caregiver services you have received, do you find it easier to care for the care recipient?” About 85% of respondents answered “yes”. The third and final outcome variable “Stress”, answers “As a result of the caregiver services you have received, do you feel less stress?” About three-fourths of caregivers answered “yes”. These variables were chosen as the outcome variables because, of the data collected, they best address caregiver burden.

Because caregivers could be referring to other services provided by the NFCSP in their responses to these three outcome variables, such as counseling and training services, and access assistance services, this study created a variable called “Other Services”, in addition to including a respite variable. Respite = 1 if the participant received respite care through the Family Caregiver Support Program. The “Other Services” variable was created by combining the responses of caregivers who stated that they have received training or education (including counseling or support groups),

received help or information from an AAA staff person, and have been provided other supplemental services. About 80% of caregivers fall into this category, while only 59.9% answered that they have received FCSP respite care. Some of these respondents overlap, but some have received one or the other. Respite is the treatment of interest, and “Other Services” will be used as a control.

The survey included several indicators of time spent on caregiving, including but not limited to hours of care on the weekend, hours of care on a weekday, and hours of care per week. This study uses an index that combines the responses to create the variable “Care Index” which ranges from 8 to 60, and has a mean of approximately 44. This variable will also be used as a control for the amount of time spent caregiving, because the amount of time a caregiver spends caregiving could potentially affect how they perceive the usefulness of NFCSP⁴¹.

The income variable is a dichotomous variable which identifies if the caregiver had a total combined household income of under \$20,000. Though the survey did include income as an ordinal variable as well, the brackets were not consistent, and therefore the results of the variable would be harder to interpret. About 24.4% of respondents indicated a household income of under \$20,000.

Other variables used as controls in this model include number of care recipients the caregiver cares for (mean= 0.348), whether or not the recipient can be left alone (18.34%), if the caregiver has a disability that is affected by caregiving (44.5%), and the year their responses were collected.

Design

This study tests three hypotheses:

1. Respite services provided by NFCSP impacts the likelihood that a caregiver responds that as a result of the caregiver services, they have more time for personal activities.
2. Respite services provided by NFCSP impacts the likelihood that a caregiver responds that as a result of the caregiver services, they find it easier to care for the care recipient.
3. Respite services provided by NFCSP impacts the likelihood that a caregiver responds that as a result of the caregiver services, they feel less stress.

This study will use a nonexperimental design and use logistic

41 Casado, Bangwa Lee. “Sense of Need for Financial Support and Respite Services among Informal Caregivers of Older Americans.” *Journal of Human Behavior in the Social Environment* 18, no. 3 (2008): 269-287.

regressions in order to estimate odds ratios. These odds ratios should identify the relationship between respite care, ease of care, time for personal activities, and stress, holding constant other variables in the model. Because this model is nonlinear, maximum likelihood will be used rather than OLS. A low mean VIF of 1.20 indicates that any collinearity present is not severe enough to cause a problem for this analysis.

Given the time and data limitations, this design was the best option to test Family Caregiver Support Program respite services. Because the National Survey of Older Americans Act Participants is funded by Title III of the Older Americans Act (Administration on Aging n.d.), there is likely a more consistent survey across the years. As mentioned previously in this paper, there are inconsistencies across various Family Caregiver Support Programs, so studying one state’s respite services would limit the generalizability of the study. However, inconsistencies among states also make studying respite services across states without focusing on a specific funding source problematic.

RESULTS

In all three models, respite care had an impact (more than double) on the caregiver experience outcome variable (time for personal activities, ease of caregiving and stress) at a .05 significance level, controlling for other variables in the model.

Time for Personal Activities

TABLE 2. RESULTS OF LOGISTIC REGRESSION FOR TIME FOR PERSONAL ACTIVITIES OUTCOME

Number of Observations= 4,854				
	Odds Ratio	Std. Err.	Z	P> z
Respite**	4.983672	0.3808633	21.02	0.000
Care Index**	0.978749	0.0028524	-7.33	0.000
Other Services**	1.458956	0.1342494	4.10	0.000
Income**	0.7399862	0.0553877	-4.02	0.000
# Caring for	0.9934425	0.0372267	-0.18	0.861
Left Alone	1.192052	0.130247	1.61	0.108
Caregiver Disability**	0.7833417	0.0514133	-3.72	0.000
Year	0.9501574	0.0376337	-1.29	0.194

**Significant at a .05 level

The odds ratio for respite care in table 2 is about 4.98 (~5). This tells us that the odds of responding “yes” to “as a result of caregiver services, do you have more time for personal activities?” with respite care use are about 5 times greater than without respite care, holding the control variables constant. By contrast, the odds of answering yes to the time for personal activities questions after using the other services are about 45% greater than without, holding the control variables constant. This result is also statistically significant. Care index, income and caregiver disability also yield statistically significant results; however, they indicate a lower likelihood of answering yes.

Ease of Caregiving

TABLE 3. RESULTS OF LOGISTIC REGRESSION FOR EASE OF CAREGIVING OUTCOME

Number of Observations= 4,841				
	Odds Ratio	Std. Err.	Z	P> z
Respite**	2.435566	0.2337167	9.28	0.000
Care Index**	0.9759377	0.0036841	-6.45	0.000
Other Services**	1.70876	0.1935546	4.73	0.000
Income	0.9897311	0.0933538	-0.11	0.913
# Caring for	0.9862116	0.0471912	-0.29	0.772
Left Alone	1.107439	0.1628168	0.69	0.488
Caregiver Disability**	0.7511704	0.0615944	-3.49	0.000
Year	0.9754239	0.0484675	-0.50	0.617

**Significant at a .05 level

The odds ratio for respite care in table 3 is about 2.44 (~2). This tells us that the odds of responding “yes” to “as a result of caregiver services, do you find it easier to care for the care recipient?” with respite care use are about twice as high as without respite care, holding the control variables constant. By contrast, the odds of answering yes to the ease of caregiving question after using the other services are about 71% greater (1.7: 1) than without, holding all other variables constant. This result is also statistically significant. Care index and caregiver disability also yield statistically significant results; however, they indicate a lower likelihood of answering yes.

TABLE 4. RESULTS OF LOGISTIC REGRESSION FOR STRESS OUTCOME

Number of Observations= 4,855				
	Odds Ratio	Std. Err.	z	P> z
Respite**	2.353295	0.1852128	10.87	0.000
Care Index**	0.9839709	0.0030254	-5.26	0.000
Other Services	1.169466	0.1149523	1.59	0.111
Income**	0.7741791	0.0603884	-3.28	0.001
# Caring for	0.919381	0.0352013	-2.20	0.028
Left Alone*	1.256511	0.1493586	1.92	0.055
Caregiver Disability**	0.790026	0.54689	-3.40	0.001
Year	0.9411118	0.0394347	-1.45	0.147

**Significant at a .05 level

*Significant at a .10 level

The odds ratio for respite care in table 4 is about 2.35 (~2). This tells us that the odds of responding “yes” to “as a result of caregiver services, do you feel less stress” with respite care use are about twice as high as without respite care, holding the control variables constant. Care index, income, and caregiver disability also yield statistically significant results; however, they indicate a lower likelihood of answering yes. In this model, other services do not yield statistically significant results. Left alone is statistically significant at a .10 level. The odds of answering yes to the time for the stress questions are about 26% greater for those whose care recipient can be left alone all day than for those that cannot be, holding all other variables constant.

CONCLUSION

Through the use of the National Survey of Older Americans Act Participants (2011-2013), which surveyed family caregivers who participated in their state’s Family Caregiver Support Program, these three logistic regressions found that there were significantly increased odds of participants answering that as a result of caregiver services, they had more time for personal activities, found it easier to care for care recipient, and felt less stress. This supports research that found favorable outcomes as a result of respite care for caregivers.

Although this study found that respite care led to positive and significant outcomes for caregivers, there are still mixed research results

surrounding the impact of respite care⁴²⁴³. These mixed results may be due to an inconsistency in the definition of respite care across programs and states⁴⁴ and the inconsistency of the respite services themselves⁴⁵⁴⁶.

In order to get a broad consensus on the effects of respite care, and potentially encourage caregivers to use the services as a result⁴⁷, more up-to-date, high quality research needs to be conducted. This recommendation has been made by nearly every source consulted for this study, including Maayan, Soares-Weise, and Lee and Mason et. al in their reviews of respite care studies⁴⁸⁴⁹. In addition, Reinhard, Feinberg, Choula, and Houser make recommendations to “develop a common definition and unit of measurement fore respite care (at the federal and state levels)”⁵⁰.

It is not likely that respite services funded by the NFCSP will standardize their programs across states, so a final recommendation to aid in furthering respite care research is to include a question about what state the caregiver is from in the National Survey of Older Americans Act Participants. With this added question, researchers can hold differences across states constant to gain more accurate estimates from their models.

Because of the rapidly aging United States population, it is unlikely that there will be a sufficient number of direct-care workers to replace

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- 42 Mason, Anne, et al. “The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People.” *Progress in Geriatrics* 55, no. 2 (2007): 290-299.
- 43 Maayan, Nicola, Karla Soares-Weise, and Helen Lee. *Respite care for people with dementia and their carers*. Oxford: The Cochrane Collaboration, 2014.
- 44 Houser, Ari, and Kathleen Ujvari . *The State of Measurement of Respite Care*. Washington, D.C. : AARP Public Policy Institute, 2012.
- 45 Feinberg, Lynn Friss, and Sandra L. Newman. “A Study of 10 States Since Passage of the National Family Caregiver Support Program: Policies, Perceptions, and Program Development.” *The Gerontologist* 44, no. 6 (2004): 760-769.
- 46 Feinberg, Lyn Friss, and Sandra L. Newman. “Preliminary Experiences of the States in Implementing the National Family Caregiver Support Program.” *Journal of Aging & Social Policy* 18, no. 3-4 (2006): 95-113.
- 47 Cangelosi, Pamela R. “Caregiver BURDEN or Caregiver GAIN? Respite for Family Caregivers.” *Journal of Psychosocial Nursing* 47, no. 9 (2009): 19-22.
- 48 Mason, Anne, et al. “The Effectiveness and Cost-Effectiveness of Respite for Caregivers of Frail Older People.” *Progress in Geriatrics* 55, no. 2 (2007): 290-299.
- 49 Maayan, Nicola, Karla Soares-Weise, and Helen Lee. *Respite care for people with dementia and their carers*. Oxford: The Cochrane Collaboration, 2014.
- 50 Reinhard, Susan C. , Lynn Friss Feinberg, Rita Choula, and Ari Houser. *Valuing the Invaluable: 2015 Update*. Washington, D.C.: AARP Public Policy Institute, 2015.

informal and family caregivers⁵¹. Respite care is meant to address the needs of temporary relief for caregivers, and is their most requested service⁵². Therefore, this is an issue that urgently needs more research and support.

51 Rose, Miriam S., Linda S. Noelker, and Jil Kagan. "Improving Policies for Caregiver Respite Services." *The Gerontologist* 55, no. 2 (2015): 302-308.

52 Reinhard, Susan C. , Lynn Friss Feinberg, Rita Choula, and Ari Houser. *Valuing the Invaluable: 2015 Update*. Washington, D.C.: AARP Public Policy Institute, 2015.

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- Cangelosi, Pamela R. "Caregiver BURDEN or Caregiver GAIN? Respite for Family Caregivers." *Journal of Psychosocial Nursing* 47, no. 9 (2009): 19-22.
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