

Number of words in abstract and body: 3,735

Number of references: 20



Effects of Respite Care Training on Respite Provider Knowledge and Confidence, and Outcomes
for Family Caregivers Receiving Respite Services

Submitted To: Home Health Care Services Quarterly

Lynn K. Ackerman, Ph.D.

Sensight Surveys LLC

Lois M. Sheaffer, B.A.

Marklund

Author Note

Lynn K. Ackerman, Ph.D., Sensight Surveys LLC; Lois M. Sheaffer, B.A., Marklund.

Correspondence concerning this article should be addressed to Lynn Ackerman, Ph.D.,
Sensight Surveys LLC, 41 Founders Pointe N., Bloomingdale, IL 60108. Email:
lynn@sensightsurveys.com.

Abstract

Respite services are vital in supporting informal caregivers in need of a break from their caregiving duties. A respite training program aimed at developing respite provider competence and improving caregiver well-being was evaluated. Trainees experienced significant growth in their perceived respite knowledge and confidence to deliver respite from pre-training to post-training. An objective core competency assessment confirmed post-training knowledge in ten core areas of respite. Family caregivers provided more favorable ratings on various measures of their well-being while receiving respite from a trained provider compared to before respite began and if respite were to end. Findings suggest that formal training prepares providers to deliver quality respite resulting in improved caregiver outcomes.

Keywords: respite training, family caregiver, stress, health, out-of-home placement

Effects of Respite Care Training on Respite Provider Knowledge and Confidence, and Outcomes
for Family Caregivers Receiving Respite Services

Caring for a loved one with special cognitive or health care needs at home can be beneficial and rewarding for family members serving as primary caregivers (Roth, Fredman, & Haley, 2015; Spillman, Wolff, Freedman, & Kasper, 2014). Yet, a substantial body of research suggests that family caregivers can become susceptible to a number of negative risk factors, such as high stress levels, mental and physical health problems, social isolation, and lost income from missed employment opportunities (Capistrant, Berkman, & Glymour, 2014; Capistrant, Moon, Berkman, & Glymour, 2012; Capistrant, Moon, & Glymour, 2012; Carr & Kail, 2012; Family Caregiver Alliance, 2017; Skira, 2015; Van Bruggen et al., 2016). The negative impact of caregiving is typically greatest for family members who provide the most care hours per week, a group who also tends to be the eldest within the family caregiver population. Unfortunately, these higher-hour caregivers are least likely to have help from others (National Alliance for Caregiving and AARP Public Policy Institute, 2015).

Without temporary relief from their caregiving responsibilities, family members become more likely to choose out-of-home placement for their loved one, which can result in higher health care costs compared to staying at home (Reinhard, Feinberg, Choula, & Houser, 2015). Further, out-of-home placement threatens the progress of policies advocating for a community services approach over institutional care (Commission on Long-Term Care, 2013; National Service Direct Workforce Resource Center, 2010). As the U.S. aging population continues to grow in size, so does the need for informal caregiving at home. More than ever before, family caregivers are being recognized as vital members of a direct care workforce that need access to services to support them in their caregiving role (Rose, Noelker, & Kagan, 2015).

According to ARCH National Respite Network and Resource Center (ARCH), respite is defined as “planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care receiver, and/or family system” (Kirk & Kagan, 2015). Despite the growing need for respite to support family members in their caregiving role, only half of the forty million primary caregivers in the U.S. report receiving unpaid help from a volunteer. Only one in three report utilizing paid help (Caregiving in the U.S., 2015).

While efforts to grow the respite workforce and improve access to respite services are needed to eliminate service gaps (Caregiving in the U.S., 2015; Kirk & Kagan, 2015), it is unclear whether receiving respite services guarantees positive outcomes for family caregivers. In general, research examining the effect of receiving respite on caregiver outcomes such as stress, physical health, quality of life, and out-of-home placement has been sparse and mixed (Maayan, Soares-Weiser, & Lee, 2014; Vandepitte et al, 2016; Whitmore, 2016). In a recent systematic review of respite care studies aimed at evaluating outcomes for dementia caregivers, Vandepitte et al. (2016) concluded that new research is needed to understand the impact of respite programs on family caregiver outcomes. Lack of clarity concerning respite’s ameliorative effects may be in part due to the absence of more granular research examining specific factors that influence the respite experience itself, such as the background and training of respite providers and the content and quality of respite activities. National respite guidelines advocate for an individualized approach to respite care that addresses each family’s unique set of circumstances (Edgar & Uhl, 2011). As such, research-supported training programs that ensure

that respite providers possess the requisite skills to deliver quality family-centered respite care are paramount.

In 2014, ARCH assembled an expert panel to understand the current state of respite research and to set future directions (Kirk & Kagan, 2015). The panel identified six key areas as important foci of future respite research: 1) Improved research methodologies; 2) Individual, family, and societal outcomes; 3) Cost-benefit and cost-effectiveness research; 4) Systems change that improves respite access; 5) Improved respite provider competence; and 6) Translate research findings into best-practice models. The present study takes steps to advance areas two and five by evaluating the impact of a nationwide respite training program aimed at developing provider competence and improving quality of life for family caregivers receiving respite.

Method

Study Design and Hypotheses

Using a pretest-posttest design, this study measured the impact of respite care training on trainee perceived knowledge and confidence. It was hypothesized that self-reported knowledge and confidence to deliver respite would increase significantly from pre-training to post-training. A pre-study focus group with untrained respite providers uncovered specific areas of concern based on their previous respite experiences (e.g., not being able to meet care recipient complex care needs, not knowing what to do in an emergency, fear of becoming ill). Since many individuals interested in providing respite care to families in their community have no previous respite experience or formal training, it is important that subjective ability and confidence to deliver respite be measured as a training outcome. To support perceived knowledge and confidence measures, the current research also hypothesized that an objective core competency assessment administered post-training would show competency in ten core areas of respite care.

Once graduates of the program were in the field providing respite to families, the study measured the impact of receiving respite from a trained provider on various aspects of family caregiver well-being. It was hypothesized that self-reported caregiver stress levels, general health status, stress-related health symptoms, opportunities to engage in desired social/recreational activities, and out-of-home placement risk would be significantly more positive during the respite period compared to thinking back to before respite began. It was also hypothesized that the prospect of losing respite would result in significantly reduced ratings on all well-being measures.

Participant Groups

Training workshop participants. Workshop participants were 895 individuals who attended the REST (Respite Educational and Support Tools) eight hour respite training workshop. REST is a nationwide Train-the-Trainer program that equips volunteers and paid workers with the skills needed to support caregivers in their home through respite. Trainees were recruited by REST trainers via collaborative organizations and agencies offering respite services to their local communities. Participants came from 126 workshops held between June of 2014 and June of 2017. The original sample of 1,109 participants was reduced to 895 due to missing data on key dependent variables.

Table 1 provides a breakdown of workshop participant characteristics. Training took place in 18 U.S. states, with the majority of trainees receiving training in Nevada (24%), Nebraska (13%), Arkansas (12%), and Illinois (11%). Most trainees self-identified as non-Hispanic (69%) and White/Caucasian (78%). Just over half (56%) reported having prior respite experience, and just over half (53%) came to training with no personal care or health care experience in their professional background. Seven out of ten (71%) trainees did not have a specific person in mind they would like to serve. Trainees varied in how often they wanted to provide respite, with most respondents selecting 1 to 3 days per month (28%), 1 to 2 days per week (25%), and 3 to 5 days per week (21%).

In an initial exploratory analysis, the prior respite experience and professional care background variables were significantly correlated with changes in respite knowledge and confidence from pre-training to post-training. Since the REST training program is designed to be suitable for all adults interested in providing respite regardless of their background, it became of interest to evaluate the impact of training separately for groups with and without respite experience and with and without a professional care background. To this end, these variables

were entered as between-subjects variables in the repeated measures analysis so their interactions with training could be evaluated.

Family caregivers. Family caregivers were 102 individuals receiving respite from a trained REST Companion™ in their home. Table 2 provides a breakdown of family caregiver characteristics. Caregivers resided in 13 states, with the majority from Arkansas (25%), Illinois (21%), Nevada (20%), and Nebraska (18%). Most self-identified as non-Hispanic (72%) and White/Caucasian (70%). Just over half (55%) were married. Relationship to the care recipient varied, with most respondents identifying themselves as other kinship caregiver (39%), spouse (21%), birth parent (20%), or son/daughter (13%). Approximately half (49%) were receiving respite free of charge, with another 25% paying out of pocket and 19% paying with a state grant voucher or waiver.

Measures

Pre and post training respite knowledge and confidence. Trainee respite knowledge and confidence were measured using 18 self-ratings developed for the present study. Twelve ratings capture perceived knowledge in the ten core areas of respite care endorsed by ARCH (2002) and coinciding with the REST training agenda. Trainees rate their knowledge using a five-point response scale ranging from 5 (Very High) to 1 (Very Low). Higher ratings express greater perceived knowledge. The remaining six ratings capture perceived confidence to deliver respite care in six areas identified as potential barriers to successful delivery in a pre-study provider focus group. Trainees rate their level of concern using a five-point response scale ranging from 5 (Very Concerned) to 1 (Not At All Concerned). Ratings of concern are reverse coded so higher ratings express greater perceived confidence.

Respite core competency. An objective assessment of respite core competency was developed for the present study. Ten multiple choice questions measure knowledge in the ten core areas of respite care (ARCH, 2002). Each question offers five answer options with one possible correct answer. A first draft of the measure was pilot tested on nine individuals who had just completed the REST training workshop to ensure readability and alignment with training goals. A review of scores along with qualitative feedback from trainees and trainers resulted in modification of two questions resulting in a final draft.

Family caregiver well-being. A variety of family caregiver well-being indicators were measured using a modified version of a respite efficacy instrument developed by ARCH in 1998 and revised in 2002 (ARCH, 2002). The original instrument was field tested in face-to-face interviews with family caregivers receiving respite. With permission from ARCH, the instrument was modified into a self-report questionnaire focused on caregiver variables relevant to the present study. The instrument is designed to capture caregiver perceptions of their well-being at three time periods throughout the respite life cycle: 1) before receiving respite; 2) currently while respite is being received; and 3) if respite were to end. On a 5-point scale, primary caregivers currently receiving respite from a REST Companion™ are asked to rate their stress levels, general health problems status, opportunities to engage in desired social/recreational activities, and likelihood of placing the care recipient in out-of-home care. In addition, respondents report the number of stress-related health symptoms they experienced before receiving respite and while respite is being received from a list of 12 common symptoms (e.g., headache, muscle tension or pain, fatigue).

Procedure

At the beginning of the workshop before training began, trainees completed a pre-test questionnaire that included the measure of perceived respite knowledge and confidence and a variety of demographic and background questions. Trainees then completed the REST eight hour training workshop, designed to provide education and training in ten core areas of respite care (see Table 3 for a listing of the ten core areas). Training utilized an adult learning model including lecture, video, demonstrations, role-playing, and group discussion. Workshops were led by care professionals from a variety of backgrounds who had successfully completed a two-day Train-The-Trainer workshop led by REST master trainers. Workshops were held in a variety of venues, including university classrooms, medical centers, churches, counseling centers, state agencies, and not-for-profit organizations. Immediately after training concluded, trainees completed a post-test questionnaire that included the measure of perceived respite knowledge and confidence and the respite core competency assessment.

Six months after trainees completed the training workshop, family caregivers they were actively serving with respite were invited to take a family caregiver survey that included the family caregiver well-being measures and a variety of demographic and background questions. Family members had the option of taking the survey online or via paper. Respondents were offered a \$10 Walmart gift card as incentive for participating in the survey.

Results

Perceived respite knowledge and confidence

Repeated measures mixed ANOVA tests were performed to analyze changes in trainee perceived knowledge and confidence from pre-training to post-training. Prior respite experience and professional care background (both binary variables) were entered as between-subjects variables in two separate analyses to test for group differences in changes in perceived

knowledge and confidence. Table 4 presents ANOVA test results. With prior respite experience as the between-subjects variable, the main effect of training on respite knowledge was statistically significant [$F(1, 877) = 985.14, p < .001$] as was the main effect of training on respite confidence [$F(1, 877) = 260.50, p < .001$], indicating that respite knowledge and confidence increased significantly for the entire sample from pre-training to post-training. The main effect of training was also significant when professional care background was entered as the between-subjects variable [$F(1, 873) = 860.74, p < .001$ for knowledge and $F(1, 873) = 237.42, p < .001$ for confidence]. All findings were in hypothesized directions with perceived respite knowledge and respite confidence increasing significantly from pre-training to post-training.

The interactions between training and prior respite experience and between training and professional care background are displayed in Figure 1, Figure 2, Figure 3, and Figure 4. All interactions were statistically significant as shown in Table 4. Post hoc paired t-tests were performed to evaluate change in knowledge and confidence from Time 1 to Time 2 for each respite experience group and professional care background group. A Bonferroni family-wise error rate adjustment was applied by dividing the alpha level of .05 by the number of t-tests performed (eight tests total). Thus, each t-value was required to meet the criterion of $p < .006$ to be deemed statistically significant. Table 5 shows mean difference scores and t-values. All t-tests were statistically significant. Respite knowledge and confidence increased significantly from Time 1 to Time 2 for all groups regardless of their prior respite experience and professional care background. Further review of the interaction line graphs suggest that trainees with prior respite experience and trainees with a professional care background began training with higher

levels of perceived knowledge and confidence than their non-experienced counterparts, but by the end of training knowledge and confidence levels were similar for all groups.

Respite core competency

Post-training respite core competency scores were explored for the total sample and for all trainee subgroups to objectively determine if trainees possessed satisfactory respite knowledge after completing training. A pass criterion of 8 or more correct answers out of a possible 10 was established a priori. A total of 648 of the 768 (84.3%) trainees who completed the core competency assessment achieved a satisfactory score of 8 or higher. Table 6 provides descriptive data for the total sample and by training state, ethnicity, race, prior respite experience, professional care background, recipient in mind, and desired frequency of respite service. For the total sample, core competency scores ranged from 0 to 10, mode and median scores were both 9, and the mean score was 8.56. With the exception of Native American / Pacific Islanders ($n = 2$), all groups had mode and median scores of 8 or higher. Group mean scores ranged from 7.00 to 9.00 with all groups surpassing the established cutoff of 8 points except Native American / Pacific Islanders ($M = 7.00$) and Asian / Asian Americans ($M = 7.75$). While exploratory in nature, descriptive data for the core competency assessment generally support the hypothesis that trainees possessed satisfactory respite knowledge at the completion of training. This hypothesis was partially supported for Native American / Pacific Islander and Asian / Asian American groups.

Family caregiver well-being

Repeated measures ANOVA tests were performed to evaluate family caregiver ratings of their stress levels, general health status, opportunities to engage in desired social/recreational activities, and likelihood of placing the care recipient in out-of-home care across three

contemplated time periods: before respite began (thinking back), now that respite is being provided (currently), and if respite were to end (imagined future). Differences in the number of reported stress-related health symptoms “before respite” compared to “during respite” were also compared. Table 7 presents group means and standard deviations at each time period along with ANOVA test results. Using Greenhouse-Geiser adjusted degrees of freedom to correct for violation of sphericity, F-values for stress, general health problems status, social/recreational opportunities, and out-of-home placement risk were statistically significant, indicating that these measures varied significantly across the three time periods. Planned contrasts revealed that self-reported stress, general health problems status, and out-of-home placement risk were significantly lower at Time 2 (during respite) than Time 1 (before respite) and Time 3 (if respite were to end). Opportunities to engage in social/recreational activities were significantly higher at Time 2 (during respite) than Time 1 (before respite) and Time 3 (if respite were to end). The mean number of reported stress-related health symptoms was significantly higher at Time 1 ($M = 5.24, SD = 3.70$) than Time 2 ($M = 3.06, SD = 3.09$). All significant findings were in hypothesized directions whereby well-being indicators were more positive during the respite period compared to thinking about before respite began and if respite were to end.

Discussion

Results Summary

Overall, individuals who participated in the REST training workshop reported substantial gains in their respite knowledge and confidence as a result of going through training. These findings were supported for trainees regardless of their demographic group membership or respite/professional care background. An objective assessment of respite core competency confirmed requisite knowledge in ten core areas of respite care for most trainee groups. Once REST Companions™ were in the field providing in-home respite, the family caregivers they served on the whole felt less stressed, healthier, more able to engage socially and recreationally, and less likely to place their loved one in out-of-home care. They also believed that losing respite would reverse these improvements.

Implications

This study is a first step in examining how formal respite training translates into competent respite care and, as a result, better outcomes for family caregivers. The role of respite provider entails more than serving as a babysitter while primary caregivers take time away from their caregiving responsibilities. The delivery of a quality respite experience involves equipping providers with skills that allow them to respond to unique family needs and situations, ranging from respecting family diversity to managing challenging care recipient behaviors. This research supports the supposition that when respite providers are educated on the core areas of quality respite, they have the tools to develop an individualized plan of care and the know-how to thoughtfully respond to unique family situations, resulting in better caregiver outcomes. Researchers, practitioners, and policy makers should work together to develop programs and policies that recognize the importance of tailoring respite care in this individualized way. Doing

so will allow family members to comfortably step away from their caregiving duties and focus on their own needs so they can build renewed energy to continue to care for their loved one.

Strengths, Limitations, and Future Directions

The goal of the REST training program is to create a nationwide network of individuals who are trained in providing quality, compassionate respite care. The program was designed for any adult wishing to provide respite care in their community regardless of their personal background. As such, a key strength of this study was the ability to test the effectiveness of the program on a large, nationwide sample. Results provide supportive evidence that the REST training workshop is universally applicable to individuals from diverse locales and backgrounds, supporting the philosophy that one need not come to training with prerequisites beyond having the desire to learn how to provide quality respite to families. The finding that Native American / Pacific Islander and Asian / Asian American groups scored lower on the core competency assessment than other racial groups deserves additional attention. If future research replicates this finding, it should be clarified if and how training could be adjusted to better serve these groups.

Another study strength was the ability to follow trainees into the field to observe the impact of their respite service on the well-being of family caregivers. By hearing directly from family members receiving respite from a REST-trained provider, we have evidence that caregivers feel better when they receive trained respite compared to not having respite. Future research would be strengthened by the addition of comparison groups. The inclusion of a no-training comparison group and a no-respite control group would help differentiate the impact of trained respite over untrained respite and no respite at all. Examination of the influence of

timing factors, such as onset, frequency, and duration of respite on caregiver outcomes would also be beneficial.

Validated measures of respite knowledge and confidence were not available at the time the present research was conducted, therefore these measures were developed to carry out the research. Future research should focus on establishing validated instruments so there is consistency in measurement across respite training studies. Both objective and subjective measures of respite provider competence are needed so the unique impact of both types can be understood. Objective indicators of caregiver stress and health (e.g., heart rate, blood pressure, stress hormone levels) would add strength to research findings.

The present research focused on how receiving respite from a trained provider impacts outcomes for family members caring for a loved one at home. This carries forward a tradition of focusing on caregiver needs and outcomes. Future research should advance our understanding of how respite quality impacts the care recipient as well as the larger family system.

References

- ARCH National Respite Network and Resource Center. (2002). *Evaluating and reporting outcomes: A guide for respite and crisis respite program managers. 2nd Edition*. Chapel Hill, NC: Chapel Hill Training-Outreach Project, Inc.
- Capistrant, B., Berkman, L., & Glymour, M. M. (2014). Does duration of spousal caregiving affect risk of depression onset? Evidence from the Health and Retirement Study. *American Journal of Geriatric Psychiatry, 22*(4), 766-770.
- Capistrant, B., Moon, J. R., & Glymour, M. M. (2012). Spousal caregiving and incident hypertension. *American Journal of Hypertension, 25*(4), 437-443.
- Capistrant, B., Moon, J. R., Berkman, L. F., & Glymour, M. M. (2012). Current and long-term spousal caregiving and onset of cardiovascular disease. *Journal of Epidemiology and Community Health, 66*(10), 951-956.
- Carr, D., & Kail, B. (2013). The influence of unpaid work on the transition out of full-time paid work. *Gerontologist, 53*(1), 92-101.
- Edgar, M., & Uhl, M. (2011). *2011 national respite guidelines: Guiding principles for respite models and services*. Retrieved from ARCH website:
https://archrespite.org/images/Books/NationalRespite_Guidelines_Final_October_2011_1MB.pdf.
- Family Caregiver Alliance. (n.d.). *Caregiver health*. Retrieved from <https://www.caregiver.org/caregiver-health>.

- Kirk, R. S., & Kagan, J. (October, 2015). *A research agenda for respite care. Deliberations of an Expert panel of researchers, advocates and funders*. Retrieved from ARCH website: https://archrespite.org/images/docs/2015_Reports/ARCH_Respite_Research_Report_web.pdf.
- Maayan, N., Soares-Weiser, K., & Lee, H. (2014). Respite care for people with dementia and their carers. *Cochrane Database of Systematic Reviews*, 16(1).
- National Alliance for Caregiving and AARP Public Policy Institute. (June, 2015). *Caregiving in the U.S. 2015*. Retrieved from http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf.
- National Service Direct Workforce Resource Center. (March, 2011). *Building capacity and coordinating support for family caregivers and the direct service workforce. Common goals and policy recommendations emerging from the CMS leadership summit on the direct service workforce and family caregivers*. Retrieved from <https://www.medicaid.gov/medicaid/ltss/downloads/workforce/cms-leadership-summit.pdf>.
- Reinhard, S. C., Feinberg, L. F., Choula, R., & Houser, A. (July, 2015). *Valuing the invaluable 2015 update: Undeniable progress, but big gaps remain*. Retrieved from AARP Public Policy Institute website: <http://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>.
- Rose, M. S., Noelker, L. S., & Kagan, J. (2015). Improving policies for caregiver respite services. *Gerontologist*, 55(2), 302-308.
- Roth, D., Fredman, L., & Haley, W. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *Gerontologist*, 55(2), 309-313.
- Skira, M. (2015). Dynamic wage and employment effects of elder care. *International Economic*

Review, 56(1), 63-93.

Spillman, B. C., Wolff, J., Freedman, V. A., & Kasper, J. D. (January, 2014). *Informal caregiving for older Americans: An analysis of the 2011 National Survey of Caregiving*. (Report to the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation). Retrieved from U.S. Department of Health and Human Services website: <https://aspe.hhs.gov/report/informal-caregiving-older-americans-analysis-2011-national-study-caregiving>.

United States Senate Commission on Long-Term Care. (September, 2013). *Report to the Congress*. Retrieved from <http://ltccommission.org/ltccommission/wp-content/uploads/2013/12/Commission-on-Long-Term-Care-Final-Report-9-26-13.pdf>.

Van Bruggen, S., Gussekloo, J., Bode, C., Touwen, D. P., Engberts, D. P., & Blom, J. W. (2016). Problems experienced by informal caregivers with older care recipients with and without cognitive impairment. *Home Health Care Services Quarterly*, 35(1), 11-24.

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Verdonck, C., & Annemans L. (2016). Effectiveness of respite care in supporting informal caregivers of persons with dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 12, 1277-1288.

Whitmore, K. E. (2016). Respite care and stress among caregivers of children with autism spectrum disorder: An integrative review. *Journal of Pediatric Nursing*, 31(6), 630-652.

Table 1

Respite Workshop Trainee Sample Characteristics (N = 895)

Characteristic	Number	Percentage
State		
Alabama	45	5.0
Arkansas	107	12.0
Arizona	7	0.8
Colorado	6	0.7
Hawaii	11	1.2
Illinois	102	11.4
Kansas	42	4.7
Massachusetts	34	3.8
Maine	6	0.7
Michigan	59	6.6
Minnesota	41	4.6
Missouri	13	1.5
Montana	12	1.3
Nebraska	118	13.2
Nevada	212	23.7
New York	58	6.5
Ohio	9	1.0
Tennessee	13	1.5

Ethnicity

Hispanic	50	5.6
Not Hispanic	615	68.7
Unknown	21	2.3

Race

African / African-American	91	10.2
American Indian / Alaskan Native	17	1.9
Asian / Asian-American	41	4.6
Multi-racial	15	1.7
Native American / Pacific Islander	3	0.3
Unknown	2	0.2
White / Caucasian	695	77.7

Prior respite experience

No	377	42.1
Yes	502	56.1

Professional care background

No	470	52.5
Yes	405	45.3

Care recipient in mind

No	636	71.1
Yes	233	26.0

Desired service frequency

Less than once per month	131	14.6
--------------------------	-----	------

1 to 3 days per month	247	27.6
1 to 2 days per week	225	25.1
3 to 5 days per week	189	21.1

Table 2

Family Caregiver Sample Characteristics (N = 102)

Characteristic	Number	Percentage
State of Residence		
Alabama	7	6.9
Arkansas	25	24.5
Colorado	1	1.0
Illinois	21	20.6
Kansas	1	1.0
Massachusetts	3	2.9
Maine	1	1.0
Minnesota	1	1.0
Montana	1	1.0
Nebraska	18	17.6
Nevada	20	19.6
New York	2	2.0
Oklahoma	1	1.0
Ethnicity		
Hispanic	10	9.8
Not hispanic	73	71.6
Unknown	6	5.9
Race		

African / African-American	11	10.8
American Indian / Alaskan Native	2	2.0
Multi-racial	2	2.0
Unknown	3	2.9
White / Caucasian	71	69.6
Marital status		
Divorced	12	11.8
Married / partnered	56	54.9
Separated	2	2.0
Single	15	14.7
Widowed	3	2.9
Relation to care recipient		
Birth parent	20	19.6
Foster care provider	2	2.0
Grandparent	3	2.9
Other kinship caregiver	40	39.2
Sibling	3	2.9
Son / daughter	13	12.7
Spouse	21	20.6
Respite pay source*		
Do not pay	50	49.0
Insurance	7	6.9
Other	11	10.8

Out of pocket	25	24.5
State grant funding	19	18.6

*Percentages sum to greater than 100% because respondents could select more than one category.

Table 3

Ten Areas of Respite Core Competency

Core Competency Area

1. Respite: Definition/Value/Your Role
 2. Abuse and Neglect
 3. Family Diversity
 4. Communication skills
 5. Universal Precautions
 6. Behavior Management
 7. Planning/Preparing Appropriate Activities, Routines, and Schedules
 8. Confidentiality
 9. Respecting Independence/Abilities of Care Receiver
 10. Caregiver Stress and Resultant Outcomes
-

Table 4

Repeated Measures Mixed ANOVA Results for the Effects of Training, Prior Respite Experience, and Professional Care Background on Respite Knowledge and Confidence

Dependent Variable and Effect	<i>MS</i>	<i>df</i>	<i>F</i>	Partial η^2
Perceived Respite Knowledge				
Training	44928.54	1	985.14**	.529
Training x Prior Respite Experience	3917.30	1	85.89**	.089
Perceived Respite Confidence				
Training	39135.25	1	860.74**	.496
Training x Professional Care Background	3949.54	1	86.87**	.090
Perceived Respite Knowledge				
Training	4791.48	1	260.50**	.229
Training x Prior Respite Experience	223.49	1	12.15*	.014
Perceived Respite Confidence				
Training	4357.97	1	237.42**	.214
Training x Professional Care Background	184.53	1	10.05*	.011

* $p < .01$. ** $p < .001$.

Table 5

Means, Standard Deviations, and Paired T-Test Results for Change in Respite Knowledge and Confidence as a Function of Prior Respite Experience and Professional Care Background

Dependent Variable and Group	Time 1	Time 2	Mean Diff	<i>t</i>
	<i>M (SD)</i>	<i>M (SD)</i>		
Perceived Respite Knowledge				
No prior respite experience	40.38 (11.77)	53.61 (6.59)	-13.23	-23.55*
Prior respite experience	48.09 (9.27)	55.29 (5.86)	-7.20	-19.23*
No professional care background	40.64 (11.46)	53.14 (6.72)	-12.50	-24.71*
Professional care background	49.71 (8.19)	56.18 (5.14)	-6.47	-17.26*
Perceived Respite Confidence				
No prior respite experience	19.57 (5.98)	23.63 (6.38)	-4.06	-14.36*
Prior respite experience	20.74 (6.54)	23.35 (7.28)	-2.62	-9.06*
No professional care background	19.26 (6.01)	23.07 (6.56)	-3.82	-14.29*
Professional care background	21.33	23.84	-2.51	-7.96*

(6.58)

(7.37)

Note: Bonferroni correction was applied to adjust for the familywise error rate. $*p < .001$.

Table 6

Respite Core Competency Scores for Total Sample and by Trainee Subgroup

Group	<i>N</i>	Min/Max	Mode	Median	<i>M (SD)</i>
Total Sample	768	0/10	9	9	8.56 (1.40)
State					
Alabama	44	4/10	9	9	8.95 (1.03)
Arkansas	87	5/10	9	9	8.92 (1.05)
Arizona	7	8/9	9	9	8.57 (0.53)
Hawaii	10	7/10	9	9	8.60 (1.17)
Illinois	86	6/10	9	9	8.55 (1.18)
Kansas	36	5/10	9	10	8.61 (1.36)
Massachusetts	30	4/10	9	9	8.10 (1.65)
Maine	2	9/9	9	9	9.00 (0.00)
Michigan	56	1/10	9	8	8.30 (1.70)
Minnesota	33	7/10	9	9	9.00 (0.87)
Missouri	13	5/9	9	9	8.23 (1.17)
Montana	12	7/10	9	9	8.42 (1.00)
Nebraska	87	0/10	9	9	8.53 (1.56)
Nevada	196	1/10	9	9	8.31 (1.59)
New York	49	4/10	9	10	8.92 (1.43)
Ohio	8	8/10	9	8	8.75 (0.89)
Tennessee	12	6/10	9	8	8.67 (1.15)

Ethnicity

Hispanic	45	2/10	9	9	8.18 (1.67)
Not Hispanic	529	1/10	9	9	8.68 (1.27)
Unknown	21	5/10	9	9	8.62 (1.32)

Race

African / African-American	82	0/10	9	9	8.17 (1.76)
American Indian / Alaskan Native	15	6/10	9	8	8.53 (1.25)
Asian / Asian-American	36	4/10	8	9	7.75 (1.46)
Multi-racial	15	7/10	8	8	8.27 (1.03)
Native American / Pacific Islander	2	7/7	7	7	7.00 (0.00)
Unknown	1	8/8	8	8	8.00 (0.00)
White / Caucasian	592	1/10	9	9	8.71 (1.29)

Prior respite experience

No	319	1/10	9	9	8.48 (1.47)
Yes	433	0/10	9	9	8.62 (1.35)

Professional care background

No	401	1/10	9	9	8.54 (1.33)
Yes	352	0/10	9	9	8.57 (1.49)

Recipient in mind

No	541	1/10	9	9	8.56 (1.40)
Yes	207	1/10	9	9	8.59 (1.33)

Desired service frequency

Less than once per month	116	1/10	9	9	8.66 (1.41)
--------------------------	-----	------	---	---	-------------

EFFECTS OF RESPITE CARE TRAINING

32

1 to 3 days per month	200	1/10	9	9	8.80 (1.29)
1 to 2 days per week	197	4/10	9	9	8.69 (1.14)
3 to 5 days per week	167	0/10	8	9	8.11 (1.69)

Note: Core competency scores can range from 0 to 10.

Table 7

Means, Standard Deviations, and Repeated Measures ANOVA Results for Change in Family Caregiver Well-Being Measures

Variable	Before	During	If respite	<i>F</i>
	respite	respite	were to end	
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>	
Stress	3.31 (1.24)	2.36 (0.94)	3.65 (1.39)	59.87*
General health status	2.56 (1.19)	1.96 (1.00)	2.94 (1.44)	45.79*
Social/Recreational opportunities	2.02 (0.96)	2.88 (0.98)	2.04 (1.21)	3.54*
Out-of-home placement risk	1.83 (1.12)	1.46 (0.82)	2.00 (1.23)	14.61*
Stress-related health symptoms ^a	5.24 (3.70)	3.06 (3.09)	---	59.87*

^aNumber of stress-related health symptoms could range from 0 to 12. * $p < .001$.



Figure 1. Interaction between training and prior respite experience on respite knowledge.

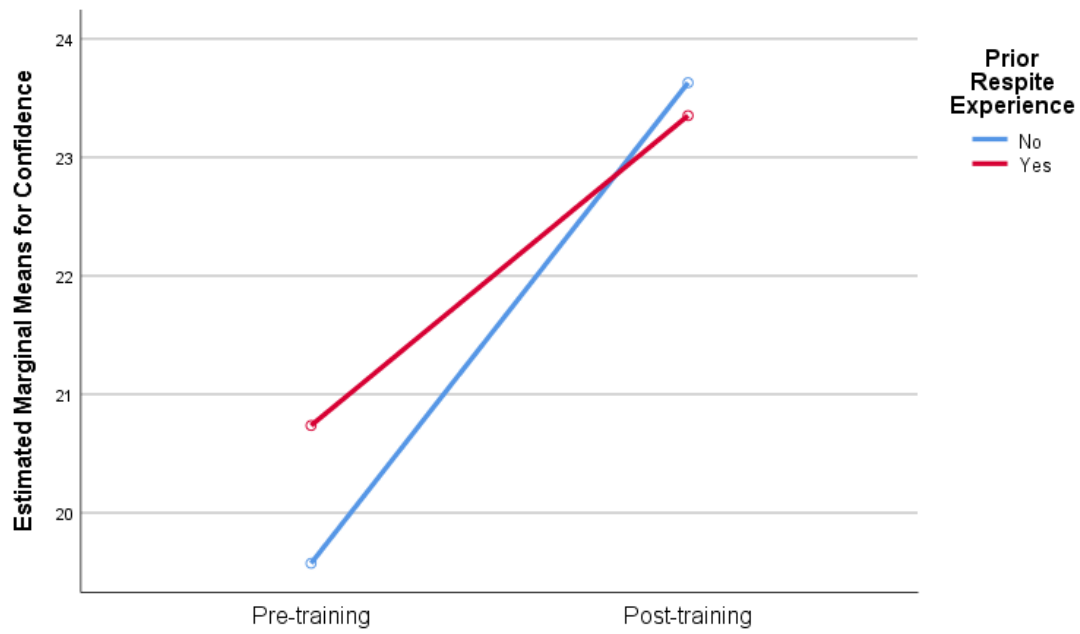


Figure 2. Interaction between training and prior respite experience on respite confidence.

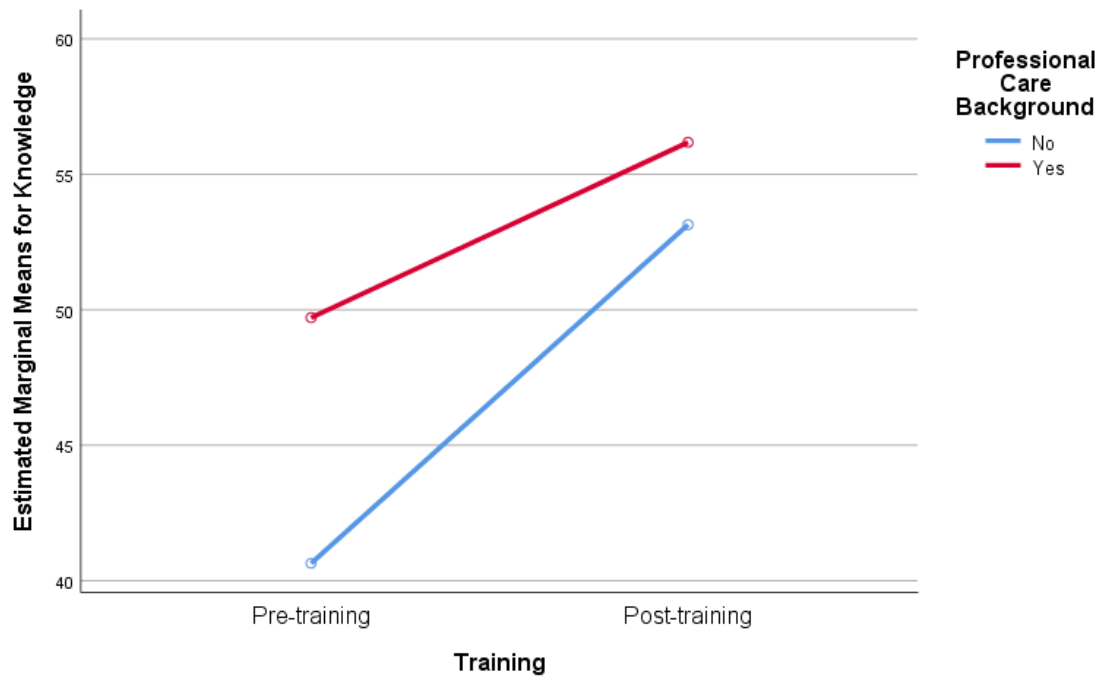


Figure 3. Interaction between training and professional care background on respite knowledge.

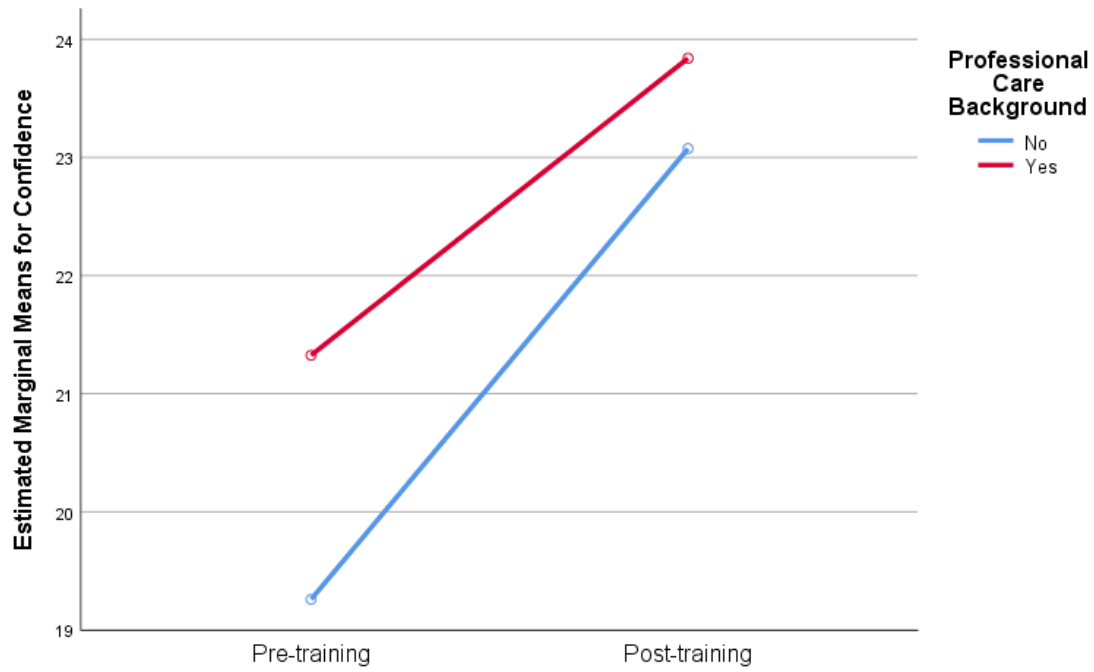


Figure 4. Interaction between training and professional care background on respite confidence.

Appendix A

Training Workshop Pre-Post Respite Knowledge and Confidence Ratings

1. Rate your level of skill/knowledge/understanding in each of the following areas of respite work:

5=Very High to 1=Very Low

The roles and responsibilities of a respite worker	5	4	3	2	1
Establishing good communication and trust with the family	5	4	3	2	1
Gathering information from the family to set up respite arrangements	5	4	3	2	1
Determining care recipient interests and abilities	5	4	3	2	1
Strategies for communicating with care recipients	5	4	3	2	1
Adapting activities to care recipient needs	5	4	3	2	1
Understanding challenging behaviors	5	4	3	2	1
Dealing with injuries and emergency situations	5	4	3	2	1
Signs of caregiver stress and coping strategies	5	4	3	2	1
Respecting different family situations and cultures	5	4	3	2	1

Keeping family information confidential	5	4	3	2	1
Preventing the spread of germs	5	4	3	2	1

2. Rate your level of concern about each of the following areas of respite work:

5=Very Concerned to 1=Not At All Concerned

Will I know how to deal with an emergency?	5	4	3	2	1
Will I be able to meet the care recipient's needs?	5	4	3	2	1
Will I put myself at risk for becoming ill?	5	4	3	2	1
Will it be difficult to keep family information confidential?	5	4	3	2	1
Will I be asked to take on more than I can handle?	5	4	3	2	1
Will I have the support and resources I need?	5	4	3	2	1

Appendix B

Post-Training Respite Core Competency Assessment

1. Your goal as a respite worker is to...
 - a. Give the caregiver a break.
 - b. Provide a meaningful experience for the care recipient.
 - c. Enrich your own life by connecting with the care recipient.
 - d. All of the above.
 - e. Answers a and b only.
2. An effective volunteer respite worker...
 - a. Plans ahead to ensure a productive visit.
 - b. Is a babysitter.
 - c. Only takes on what they believe they can handle.
 - d. All of the above.
 - e. Answers a and c only.
3. When communicating with an individual in your care, it is helpful to...
 - a. Pay attention to non-verbal signals.
 - b. Ask questions if you do not understand what he/she is saying.
 - c. Talk to the individual about choices he/she can make.
 - d. All of the above.
 - e. All but answer b.
4. A leisure interests survey can be used to help the respite volunteer...
 - a. Learn what the care recipient enjoys doing.
 - b. Find out what the care recipient can do independently.

- c. Plan for future visits.
 - d. All of the above.
 - e. Answers a and c only.
5. Which of the following is a good question to ask yourself when planning activities with a person in your care?
- a. What tasks can they do independently?
 - b. What are their recreational interests?
 - c. How can I adapt activities to ensure they are fun or productive?
 - d. All of the above.
 - e. Answers a and b only.
6. Which of the following statements about understanding challenging behaviors is TRUE?
- a. There is nothing I can do to minimize behaviors like rocking, excessive banging, and biting.
 - b. Repetitive behaviors are not influenced by the environment.
 - c. Only individuals with special needs experience sensory overload.
 - d. All of the above.
 - e. None of the above.
7. What should you do first if a medical emergency arises while you are providing respite care?
- a. Move the person.
 - b. Try to apply first aid or CPR.
 - c. Call 911 then the caregiver.
 - d. Inform the caregiver.
 - e. None of the above.
8. What can you do to help when a caregiver seems stressed out?

- a. Inform your respite point of contact (e.g., your REST trainer, the REST office, or other identified support).
 - b. Offer the caregiver self-assessment questionnaire.
 - c. Share the “How Will I Take Care of Myself” handout.
 - d. All of the above.
 - e. Answers b and c only.
9. Which of the following can build trust with a family to whom you are providing respite?
- a. Honor your time commitment to the family.
 - b. Respect family cultural or religious practices.
 - c. Share personal information about the family with others in your community.
 - d. Follow the care recipient’s schedule as instructed.
 - e. All but answer c.
10. What is the single most important precaution for preventing the spread of germs if you or the person in your care has a contagious illness?
- a. Changing clothes.
 - b. Properly cleaning toys, utensils, and personal care items.
 - c. Washing hands.
 - d. Wearing disposable latex gloves.
 - e. Wearing a mask.

Appendix C

Family Caregiver Outcome Ratings

1. Please tell us about your stress levels.

BEFORE receiving respite, how "stressed" were you as a result of caring for your family member?

Not at all Slightly Moderately Very Extremely

NOW that you are receiving respite, how "stressed" are you as a result of caring for your family member?

Not at all Slightly Moderately Very Extremely

If respite care were to END, how "stressed" would you be as a result of caring for your family member?

Not at all Slightly Moderately Very Extremely

2. Individuals who are stressed can experience any of the following symptoms: headache, muscle tension or pain, chest pain, fatigue, change in sex drive, stomach upset, sleep problems, anxiety, restlessness, lack of motivation or focus, irritability or anger, sadness or depression.

BEFORE receiving respite, how many of the above stress-related symptoms did you experience?

NOW that you are receiving respite, how many of the above stress-related symptoms do you experience?

3. Please tell us about your health in relation to your caregiving responsibilities. In these questions, "health" includes physical, mental, and/or emotional health.

BEFORE receiving respite, did your caregiving responsibilities contribute to any health

problems you may have?

Not at all Slightly Moderately Very Extremely

NOW that you are receiving respite, do your caregiving responsibilities contribute to any health problems you may have?

Not at all Slightly Moderately Very Extremely

If respite were to END, would your caregiving responsibilities contribute to any health problems you may have?

Not at all Slightly Moderately Very Extremely

4. Please tell us about your opportunities to engage in social/recreational activities of your choice.

BEFORE receiving respite, were your opportunities and time to engage in social/recreational activities sufficient?

Not at all Slightly Moderately Very Extremely

NOW that you are receiving respite, are your opportunities and time to engage in social/recreational activities sufficient?

Not at all Slightly Moderately Very Extremely

If respite were to END, would your opportunities and time to engage in social/recreational activities be sufficient?

Not at all Slightly Moderately Very Extremely

5. Please tell us about your views concerning out-of-home placement.

BEFORE receiving respite, did you consider placing your family member in some form of out-of-home living arrangement?

Not at all A little Moderately Very seriously Extremely

seriously

NOW that you are receiving respite, do you consider placing your family member in some form of out-of-home living arrangement?

Not at all A little Moderately Very seriously Extremely
seriously

If respite were to END, would you consider placing your family member in some form of out-of-home living arrangement?

Not at all A little Moderately Very seriously Extremely
seriously