
Effect of respite care training on the knowledge, attitude, and self-esteem of volunteer providers

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Abstract

This pilot study explored the effect that respite care training had on volunteers' knowledge about Alzheimer's disease (AD), their attitudes toward the cognitively impaired, and their self-esteem. Volunteer respite providers (n = 52) were recruited and participated in four different day (seven-hour) respite care training programs. The sample was predominantly female (85 percent) and white (90 percent). Knowledge about AD increased significantly after respite training (p < .001), and attitudes toward someone who wanders were also significantly improved (p = .026). Overall, the findings support the immediate effectiveness of the respite training program.

Key words: caregiving, respite care, social support

Introduction

Family caregiving is an important factor in preventing and delaying institutionalization of the elderly.¹ The willingness of the family to provide care results in a quality of caregiving that is not easily duplicated. However, the stress and strain placed on the caregiver's physical, financial, social, and emotional well-being have been well-documented in the literature.¹⁻⁶ Respite care has been found to be the most requested and needed service among caregivers⁷ but is underutilized^{8,9} and often the least available.¹⁰

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As the use of respite has increased, more researchers have been looking at the effect of respite care on the caregiver as well as the impaired person.¹¹⁻¹³ An antecedent question to whether respite care "works" is whether those who are trained to provide respite care are trained adequately. Of interest also was the effect that the training has on the volunteers' sense of self-worth, since many volunteers reported that they believed they were getting more out of the respite experience than the caregiver. Generally, the effect of respite training on volunteers has not been studied. The purpose of this study was to investigate the effect respite care training had on volunteers' attitudes toward the cognitively impaired, knowledge about Alzheimer's disease (AD), and self-esteem.

Background

Respite care has been found to delay admission to a nursing home,¹³⁻¹⁵ increase caregiver satisfaction,^{13,16} and reduce caregiver stress.^{17,18} Improvements in caregivers' physical and emotional health have also been reported.¹³

Even though research on respite care is increasing, very little research has been conducted on *providers* of respite care. Almost no research was found evaluating the effectiveness of respite training programs or determining what type of person most appropriately provides respite care. Pearson and Deitrick¹⁹ discussed the development of an in-home respite care program that required 12 hours of educational training, but did not evaluate the effectiveness of the respite training.

Attitudes toward the impaired person became of interest in the present study when the evaluation of a previous program identified the problems that trained volunteers perceived when initiating in-home respite.²⁰ Volunteers

were reluctant to initiate such care out of fear of behavior problems of persons with AD. Researchers in another caregiving project²¹ also found the service aspect of initiating respite care to be the most difficult component of the program to implement. Trained volunteers reported two consistent themes: fear of the cognitively impaired person's behavior, and a lack of information about dementia as well as how to manage cognitively impaired persons. The training program examined in this article was designed to reduce that fear and to increase knowledge about AD.

Respite care training was originally developed as a way to enhance a volunteer's self-efficacy—the belief that one has the ability to manage specific situations.²² A volunteer's belief in their ability to manage the impaired person in the caregiving situation would be expected to increase their self-worth. It was thus expected that the training program would have a positive effect on the self-esteem of the volunteer providers, an outcome that had also been suggested by previous anecdotal reports by volunteers to the investigators.

No previously published research has examined the effect of respite care training on volunteers' knowledge about AD, their attitudes toward the cognitively impaired, or their self-esteem. Thus, the initial pilot study described in this article was designed to explore the effect that respite care training had on each of these areas. We hypothesized that the training program would have a positive effect on the volunteers' knowledge, attitudes, and self-esteem. Because modern volunteers have many competing demands/roles, analyses were also performed to examine any differences that might exist among subgroups based on demographic characteristics of the respite volunteers (e.g., age, sex, race, marital status). We also examined their reasons for volunteering and any personal experiences that might be helpful in their role as respite providers.

Method

Design

A pre- and post-test design was used to determine the effect of the respite care training; that is, each of the research instruments was administered to each of the study participants both prior to and immediately following the training.

Sample

The sample consisted of volunteers recruited through the University of Louisville School of Nursing's Volunteer Caregivers Program from various local interfaith

groups who were willing to assist caregivers of memory impaired persons in the community. (Volunteers from other community groups were not excluded.) Caregivers who were consumers of the respite program were referred from a coalition of local adult daycare centers, community agencies, and faith groups. Caregivers were interviewed by a clinical nurse specialist (CNS) or trained interviewers, and permission was requested to contact their minister/spiritual leader. The minister then was asked to send a volunteer from the congregational faith group to be trained. The clergy person was also asked to refer a member (preferably a healthcare professional) to act as the local coordinator to organize/report the activities of the congregational volunteers and matched caregivers. The match of caregiver to volunteer was made after the training was completed. Caregiver preferences for gender and religion of volunteer were honored wherever possible.

The power calculation for this study focused on the detection of significant changes in the participants' knowledge, attitudes, and self-esteem between pre- and post-test. A sample size of $n = 50$ participants would yield 93 percent power for detecting a medium effect size (0.5) in the change between pre- and post-test using a significance level of .05.

Respite training

The respite care training was held in the meeting room of a local extended care facility. Data were collected during four separate seven-hour programs. The training, taught by nurses and other professionals working with persons with dementia, used an adult learning model, and included lecture, video, panel discussion, role modeling, and group discussion. Volunteers were trained to encourage caregivers' use of support groups and adult daycare. The training employed two panel discussions. The first included stories from a program volunteer and an enrolled caregiver. The second included congregational coordinators giving examples of how they had set up this respite program in their own congregations. Another segment presented a role-model of the volunteers' first home visit, including giving clear expectations for the volunteer and caregiver. Figure 1 shows a topical outline of the training. Volunteers were expected to donate two to four hours of respite care per week after the training.

Conceptual definitions and instruments

Demographic data on the age, sex, race, education, marital status, employment, and religious denomination of the study participants were collected at the beginning

of the program. The following measures were administered at the beginning and end of the program in order to evaluate the effectiveness of the training.

Attitudes toward the cognitively impaired. Attitudes were defined as the participant's viewpoint or perspective of the cognitively impaired person. Participants' attitudes were measured using five behavioral concepts on a semantic differential scale²³ that reflected their attitudes toward the cognitively impaired. Behaviors were chosen according to anecdotal reports of previous volunteers about the problem behaviors they most feared in a cognitively impaired person: forgetfulness, inability to control bowels, inability to control urination, being up all night, and wandering away. Attitude items consisted of making judgments about these behaviors for each of the 12 bipolar adjectives used by Osgood et al.²³ Each of the five problem behaviors was rated using a 6-point scale ranging from extremely pleasant (6) to extremely unpleasant (1). Half of the 12 bipolar adjectives were presented with the positive adjective first and half were presented with the negative adjective first. Thus, any bias resulting from the tendency to choose the highest or lowest response category for every question was accounted for.²⁴ The attitudes assessed were global and not specific because the match between caregiver and volunteer had not yet been made. These matches were made following the end of the training program. A high score indicated a positive attitude toward the person with cognitive impairment. Alpha coefficients for the five scales in the present study were .83 (forgets), .60 (wanders), .55 (up at night), .82 (incontinent of urine), and .85 (incontinent of bowels).

Knowledge about AD. Knowledge was defined as facts that a person has learned about AD and was measured using a 10-item test developed by the investigators. The test (Figure 1) consisted of five true-false questions and five multiple-choice questions. The questions tested factual information about AD that had been covered in the respite training program. The 10 items covered common facts about AD and how to manage persons with AD. Each item was scored as 1 (correct) or 0 (incorrect). Face validity was determined to be high by two nursing faculty members who are leaders in geriatric care and research. They agreed that the 10 items adequately represented the domain of AD knowledge. Perhaps because of the small number of items, the alpha value of only .25 was obtained using the Kuder-Richardson formula 20.

Self-esteem. Self-esteem, defined as how the volunteer appraises or regards themselves, was measured using Rosenberg's (1968) Self-Esteem Scale, which consists of ten items answered on a 4-point Likert scale from strongly agree to strongly disagree. Since all items of the scale

revolve around liking of the self, the scale probably measures the self-acceptance aspect of self-esteem more than it does other factors.²⁵ The scale has a reproducibility coefficient of .92 and over a two-week period had a test-retest reliability of .85.²⁵ Rosenberg also reported that the scale had satisfactory convergent validity when correlated with similar measures and clinical assessment. The alpha coefficient in the present study was .80.

Open-ended questions. After completing the training program, participants were asked open-ended exploratory questions about their reasons for volunteering for the training and their life experiences that might help them in their roles as volunteer respite providers.

Procedure

All persons were asked to participate when they arrived for the respite care training program. Each potential participant received a copy of the informed consent explaining the purpose and voluntary nature of the study, and the university committee review for protection of subjects' rights. All persons agreed to participate. A copy of the demographic data sheet, and the attitudes toward the cognitively impaired, knowledge about AD, and self-esteem questionnaires were then given to the participant for the pretest. Completion of the measures took approximately 20 minutes. At the end of the training, the participants completed the same questionnaires for the post-test.

The data analysis proceeded in two steps. First, paired t-tests were used to examine the effect of the training program on knowledge about AD, attitudes toward the cognitively impaired, and self-esteem. Next, the effect of demographic characteristics on changes in these variables was explored using analysis of covariance (ANCOVA). A Bonferroni adjustment was used to control the family-wise error rate at .10 for each of the knowledge, attitude, and self-esteem variables. (A "family" of tests is defined to consist of the ANCOVA tests for the seven demographic variables: gender, age, race, marital status, employment status, education, and religious denomination.) A content analysis was performed on the responses to the open-ended questions in order to determine themes related to reasons for participating in the training program and life experiences that would be relevant to providing respite care.

Results

Fifty-two persons, none of whom were kin, participated in the study. Their mean age was 55.9 (SD = 13.6; range 23-79); and 61 percent were under age 60. Table 1 presents the demographics of the sample. The sample was

Table 1. Demographic characteristics of the sample

Characteristic		n	Percent
Total		52	100
Sex	Female	44	85
Age ^a	20 – 49	19	37
	50 – 59	12	24
	60 – 69	10	20
	70 – 79	10	20
Race ^a	White	46	90
	Non-white	5	10
Marital status	Married	32	62
	Widowed/divorced	10	19
	Single	10	19
Employment ^a	Employed	31	61
	Not employed	20	39
Education	No college	24	46
	College graduate	28	54
Religious denomination ^b	Protestant	31	63
	Catholic	11	22
	Christian	7	14

^a 1 missing case; ^b 3 missing cases.

predominantly white, female, married, and college-educated. The majority indicated affiliation with a Protestant denomination; 22 percent were Catholic. As participants were recruited from faith groups, this sample may not be representative of volunteers who did not attend church.

Changes in attitudes, knowledge, and self-esteem. Following the training, the participants' knowledge about AD significantly increased and their attitude toward the person who wanders significantly improved (Table 2). Analyses were performed to see if differences existed in improvement in knowledge or attitude toward

the person who wanders for each of the demographic subgroups given in Table 1. Using the Bonferroni-adjusted significance level of $.10/7 = .014$, none of the demographic comparisons were significant, indicating that the positive effect of the training on AD knowledge and attitude toward the person who wanders was the same regardless of the demographic characteristics of the participant.

Of the 52 participants, 35 responded to an open-ended question on the demographic data sheet requesting them to share the reason they wanted to volunteer for this training. Content analysis indicated that the narratives could be classified according to three themes: "knowledge" (n = 15, 29 percent), "to help someone" (n = 7, 13 percent), and "family member in need" (n = 13, 25 percent). The third theme related to someone attending the training to help prepare to care for their own family member.

When participants were asked which of their life experiences might help prepare them for supporting a caregiver, three patterns were identified. Of the 49 participants who answered the question, 22 (42 percent) identified "caring for a family member." Another 14 (27 percent) had professional experience, including one registered nurse and one social worker; only 13 (25 percent) had no experience. Past experience with caregiving (especially caring for a family member) was a major pattern that appeared here and also in the report of Robinson and Clemons.²⁰

Discussion

The characteristics of the potential respite volunteers in this study are similar to those in other reports about care providers. The sample was overwhelmingly white and female; only eight men participated in the training. Female family members have consistently been found to be the main source of support for care recipients,²⁶ and caregiving has traditionally been seen as a female responsibility. The majority (62 percent) of the participants were married. Interestingly, the potential respite volunteers fit the same description as the caregivers described by Theis et al.: married, white, female, and college-educated.¹³ When asked why they came to volunteer training, 25 percent indicated that they had a family member in need of care. Therefore, many of the subjects may have participated in the training just to obtain information about AD. The findings of this study are consistent with other literature indicating families serve a major caregiving function in society,^{27,28} and identify the need for more education on caregiving. A more complete identification of reasons for coming to respite care training is needed in future studies. If family

Table 2. Paired t-tests for respite training

Variable		M	SD	t	df	p
Knowledge	pretest	8.4	1.7	3.93	43	.001**
	post-test	9.3	0.9			
Attitude—forgetful	pretest	38.8	7.6	1.64	30	.11
	post-test	42.2	8.3			
Attitude— incontinent bowels	pretest	38.2	9.8	.74	26	.47
	post-test	39.9	10.8			
Attitude— incontinent urine	pretest	40.3	10.5	-.44	26	.66
	post-test	39.7	9.2			
Attitude— up at night	pretest	38.8	9.2	1.31	29	.20
	post-test	40.9	11.0			
Attitude— wandering	pretest	38.7	8.1	2.36	27	.026*
	post-test	42.1	9.0			
Self-esteem	pretest	41.3	4.6	.41	44	.69
	post-test	41.5	4.7			

* p < .05; ** p < .001.

caregivers are identified, a program may be needed whereby family caregivers and volunteers are trained together in study circles.²⁹

Following the training, informal discussions with the 52 study participants indicated that only 25 of them (58 percent) were willing to volunteer to provide respite care. This is consistent with the qualitative analysis described above, which suggested that 25 percent of the participants attended the training in order to learn how to better care for their own family member, rather than to prepare for volunteering to provide respite care for someone outside their family.

The majority (60 percent) of the study participants were employed, supporting the earlier finding²⁰ about the multiple roles of volunteer providers of respite care. It was surprising that such a high percentage of married (62 percent) and employed (60 percent) individuals, with busy lifestyles and multiple competing roles, were considering volunteering. It might be that recruitment strategies using church/faith congregations produced

the most active persons who were already combining multiple roles. Of the participants, 42 percent had personal experience with caregiving. Personal experience may also make the potential volunteer respite provider more aware of the multiple needs of the caregiver, resulting in greater willingness to volunteer to help other caregivers. Past experience makes people comfortable in similar situations. Pillemer and Sutor³⁰ examined the benefits of bringing together current and former caregivers. The presence of “experientially similar” individuals in the caregiver’s social network was strongly associated with decreased depression, especially for those caregivers in more stressful caregiving situations. In general, former caregivers were seen as less likely to criticize, abandon, or make caregiving more difficult for current caregivers. Strategies for mobilizing past caregivers within existing social networks or one-on-one matching of former caregivers with current caregivers may provide beneficial support interventions for caregivers.³⁰

Please circle "T" if the statement is true or "F" if the statement is false.

- | | | |
|---|---|---|
| T | F | 1. AD is curable. |
| T | F | 2. The cause of AD is not known. |
| T | F | 3. AD victims can be aware that something is wrong with them. |
| T | F | 4. Persons can have similar symptoms to victims of AD but have other illnesses. |
| T | F | 5. At the final stage of AD, the patient may be completely dependent. |

Please circle the letters (a, b, c) that correspond to the correct answer.

6. An AD patient will respond best to:
- a. new situations
 - b. changes in routine
 - c. routine
7. When an AD patient begins to wander away:
- a. chase after him/her and admonish him/her
 - b. follow, join person as he/she walks and quietly bring him/her back
 - c. try to "pep-up" the person
8. When communicating with an AD patient:
- a. speak as you would to any normal adult person
 - b. use short words and sentences
 - c. write out what you want to say
9. At mealtime, the AD patient will:
- a. not need much extra help eating
 - b. need instructions: when to pick up the fork, etc.
 - c. enjoy eating from colorful, floral dishes
10. If an AD patient refuses to cooperate:
- a. show him/her that you are very angry
 - b. try to find out why
 - c. stop for a few minutes and try again

Figure 1. Knowledge about Alzheimer's disease (AD).

Effect of the training

Participants' knowledge increased significantly immediately after the training. Attitude toward the person who wanders was also significantly improved. Even though self-esteem and all but one of the attitude dimensions showed no statistically significant improvement between pre- and post-test, examination of the mean post-test scores suggested improvement in each variable except attitude toward urinary incontinence. These results suggest that the training program had an immediate positive effect except for attitude toward urinary incontinence.

Because urinary incontinence is a frequent precipitor of nursing home admission, more information and interventions may be needed to prepare individuals to deal with it. Overall, the findings of the present study support the immediate effectiveness of the respite training program.

The validity of using an immediate post-training evaluation might be questioned. It is uncertain whether the current evaluation measured acquisition of new information or whether it just served as a measure of immediate recall. A resurvey at one to four weeks might help ascertain whether gains in knowledge were permanent. Future evaluations might also look at the difference between

immediate post evaluation and one potentially modified by the experience of respite caregiving. Resurveying the participants may also be needed at six and 12 month intervals to determine the continuing effect of the training over time and to ascertain the benefits of volunteering. Booster training may also be needed to enhance retention of volunteers. More knowledge is needed about how these time intervals change sensitivity to the training and enhance self-esteem.

Another limitation of this study was that the attitude dimensions used to describe the impaired elder were all indicative of dependent behaviors (forgetfulness, bowel incontinence, etc.). This may have had an unexpected negative impact on those study participants who were already involved in caregiving. Focusing only on the negative aspects of care recipient behavior is unlikely to produce a positive attitude toward or an understanding of persons with dementia.³¹ In future research, the positive, rewarding aspects of volunteer caregiving will also be included in the attitude questions.

Another limitation involves the use of a self-esteem instrument as a global measure of self-efficacy. Steffen et al.³² argue that the concept of self-efficacy should *not* be confused with global self-esteem. Self-efficacy is identified as a separate concept pertaining to specific judgments about competent performance in a given specific situation. Steffen et al. revised and evaluated a global measure of perceived self-efficacy to make it applicable to specific family caregiver tasks. This tool might be further altered for use with respite volunteers. The development of other tools might hold promise for explaining variability in a volunteer's motivation to provide respite care. Understanding each volunteer's beliefs about the ability to perform respite caregiving may help identify areas of vulnerability in caregiving skills. Thus, specific areas for improvement might be targeted for further training. In this way, self-efficacy for volunteers might be increased.

Recommendations for further research

Respite programs (in-home, short-term relief) are a promising source of supplemental care for persons with dementia and provide support to their caregivers. Increasingly, community agencies are developing programs to involve volunteers in respite care. These services are basically nonmedical in nature, and volunteer respite providers are an economical way to maintain services.^{7,27} A better understanding of what determines strong respite programs and quality volunteers would be of great benefit. Future recruitment efforts for training might seek healthy retirees who have experience in caregiving. Former caregiver families might be located with the help

of participating nursing homes that can identify family members of current or past residents. In this way, knowledge about more successful methods of recruitment for respite providers may be increased. Mechanisms to help identify future providers with desired qualities who are suited to the tasks of caregiving will contribute not only to the quality of care but also to retention of respite providers. This in turn should reduce costs and enhance the affordability of respite care. High cost may currently be a major deterrent to respite care use.

The study needs to be replicated with a larger sample. Special recruitment models are needed to attract a more diverse population of potential volunteers, since this sample was overwhelmingly white and predominantly female. More research is needed about the relationship between past caregiving experience and motivation to volunteer. How do caregiver and noncaregiver volunteers differ? Do people with experience in caregiving volunteer because of empathy, comfort with the situation, or because they more easily see the need? Which benefits does volunteering offer for former caregivers? More open-ended, qualitative questions about their former caregiving experience might yield insight into what motivates or deters former caregivers to volunteer.

Summary

Respite care training significantly increased participants' knowledge about AD and improved their attitude toward a person who wanders. Future training efforts need to focus on enhanced commitment to provide respite care. Because only 58 percent of the participants were willing to volunteer after the training, additional training experiences may need to be provided. More research about the training and education of volunteer respite care providers is needed to gain knowledge about the recruitment and retention of these workers.⁷ Recruiting and retaining volunteer respite providers is one way to offer these benefits at a lower cost, thus making respite care available and affordable to more caregivers.

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29. Percent Paid and/or Requested Circulation (Do not include 18g items 18g)			74.5%		90.9%	
30. Publication of Statement of Ownership Publication required. Will be printed in the <u>Nov/Dec 2003</u> issue of this publication. <input type="checkbox"/> Publication not required.						
31. Signature and Title of Editor, Publisher, Business Manager, or Owner <i>Richard A. DeVito</i> Date Sept 30, 2003						
32. Certify that all information furnished on this form is true and complete. I understand that anyone who furnishes false or misleading information on this form or who omits material or information requested on the form may be subject to criminal sanctions (including fines and imprisonment) and/or civil sanctions (including civil penalties).						
Instructions to Publishers						
1. Complete and file one copy of this form with your postmaster annually on or before October 1. Keep a copy of the completed form for your records.						
2. In cases where the stockholder or security holder is a trustee, include in items 10 and 11 the name of the person or corporation for whom the trustee is acting. Also include the names and addresses of individuals who are stockholders who own or hold 1 percent or more of the total amount of bonds, mortgages, or other securities of the publishing corporation. In item 11, if none, check the box. Use blank sheets if more space is required.						
3. Be sure to furnish all circulation information called for in item 15. Free circulation must be shown in items 18d, e, and f.						
4. Item 18c. Copies not Distributed, must include (1) newspaper copies originally stated on Form 3541, and returned to the publisher; (2) estimated returns from news agents, and (3) copies for office use, leftovers, spoiled, and all other copies not distributed.						
5. If the publication had Periodicals authorization as a general or requester publication, this Statement of Ownership, Management, and Circulation must be published; it must be printed in any issue in October or, if the publication is not published during October, the first issue printed after October.						
6. In item 16, indicate the date of the issue in which this Statement of Ownership will be published.						
7. Item 17 must be signed.						
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