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Powerful Tools for Caregivers, a Group Psychoeducational Skill-Building Intervention for Family Caregivers

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ABSTRACT

Introduction: Care providers consistently report negative consequences to their mental health as a direct result of their caregiving responsibilities. Specifically, they describe higher levels of distress, mental health problems, and depressive symptoms compared to their non-caregiving matched controls. Powerful Tools for Caregivers (PTC) is a national program that aims to empower caregivers to better care for themselves and enhance their self-efficacy. The purpose of the present study was to determine and quantify the effectiveness of the PTC program through pre/post data analysis.

Methods: PTC intervention was evaluated at two questionnaire time points: pre-PTC and post-PTC between June 30, 2004 and Oct 16, 2013. Paired sample t-tests ($n=409$) were conducted using SPSS Statistics Version 22 (IBM Corp., Armonk, NY).

Results: PTC increased caregivers who conducted self-care behaviors, who demonstrated self-efficacy, management of depressing emotions and those who used community resources.

Conclusion: PTC results in caregivers reporting that they are taking better care of themselves, reacting to their emotions in a healthier manner, gaining more confidence in their caregiving abilities and coping skills, and becoming more knowledgeable about receiving assistance from their community resources.

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Introduction

Powerful Tools for Caregivers (PTC) is a national program sustained by extensive collaborations with community-based organizations.¹ PTC is a train-the-trainer model program with a detailed, scripted curriculum. The PTC course is a group psychoeducational skill-building intervention that aims to empower caregivers to better care for themselves and enhance their self-efficacy.

The PTC program and all materials were developed over 3 years of pilot testing, refinement, and evaluative research at Legacy Caregiver Services in Portland, Oregon and is based on the Chronic Disease Self-Management Program developed at Stanford University.² The program has been offered since 1998, over 1,700 Class Leaders have been trained in more than 30 states, and its materials have reached over 70,000 caregivers.¹

As reported by Saltzman, in 2004 the Community Health Foundation (now the Health Foundation for Western and Central New York) provided funding to the Erie County Caregiver Coalition and the University at Buffalo, School of Public Health and Health Professions, to bring PTC to Western New York.³ In 2007, PTC received the National Family Caregiver Award for innovation, responsiveness and effectiveness from the National Alliance for Caregiving and the Met Life Foundation. In 2009, PTC received the Network of Multicultural Aging Excellence Award from the American Society on Aging/AARP.

The program is delivered in six weekly sessions, each lasting about two and one-half hours. Classes are scheduled at different times and locations in the greater metropolitan Buffalo area, and there are approximately ten to fifteen participants in each class. In the six

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weekly sessions, family caregivers develop a wealth of self-care tools in which to reduce personal stress, change negative self-talk, communicate their needs to family members and healthcare/service providers, communicate more effectively in challenging situations, recognize the messages in their emotions, deal with difficult feelings, and make tough caregiving decisions (e.g. medical, financial). Class participants also receive a text specifically developed for the course which supports the curriculum and includes additional information such as advice on how to access and evaluate community services.

However, the efficacy of this highly acclaimed program has not been determined. Some components of the PTC questionnaire not extensively investigated in other studies involving caregivers were health changes specifically related to diet and physical activity. Thus, the purpose of this novel study was to determine and quantify the effectiveness of the PTC program through pre/post data analysis.

Materials and methods

Evaluation of the PTC intervention was accomplished using a quasi-experimental, pretest-post-test design that had two data collection time points: pre-PTC and immediately post-PTC. Upon class registration, the program coordinators at Erie County Senior Services (ECSS) sent PTC class registrants (i.e. caregivers) a packet containing an informed consent and a pre-course questionnaire. Caregivers who signed and returned the consent and returned the pre-course questionnaire to ECSS were enrolled into the evaluation study. The ECSS program coordinators also sent post-course questionnaires to participants who had signed consent forms. Questionnaires were sent to participants immediately post-PTC. All mailings came from and were returned to the program coordinators at Erie County Senior Services (Table 1).

Data collected in the questionnaires encompassed caregiver demographics (Tables

2 and 3), as well as some care recipient demographics such as diagnosis, relationship to caregiver, cognitive status, and level of assistance the care recipient required. Other data collected included measures of caregiving impact, caregiver self-efficacy, caregiver self-esteem, feelings of anger, guilt, and depression, social support, and use of community resources, as well as a PTC course evaluation. Data were collected between 30 June 2004 and 16 October 2013, comprising a total of 1,038 caregivers. The purpose of this analysis was to measure any changes in caregiver self-care behaviors (e.g. increased exercise, use of relaxation techniques and medical check-ups), management of emotions (e.g. reduced guilt, anger, and depression), self-efficacy (e.g. increased confidence in coping with caregiving demands), and use of community resources (e.g. increased utilization of local services and people) after the PTC course as compared to before the PTC course. All experiments were performed in compliance with the relevant laws and institutional ethical guidelines of the University at Buffalo Health Sciences Institutional Review Board.

All data were first sorted and rectified for non-matching pre- and post-PTC caregiver ID codes, similar pre/post questions were determined, and responses were aligned and coordinated. Of the 1,038 total caregivers whose data were collected, 409 completed both the pre-PTC and post-PTC questionnaires. Consequently, it was the data of these 409 caregivers were analyzed using SPSS Statistics Version 22 (IBM Corp., Armonk, NY).

Variables were further recoded into conceptually relevant categories to ease analysis (e.g. low, med, and high). Frequencies were computed for all nominal, Likert-style variables. All data was normally distributed. Means and standard deviations were computed for all scale data. To determine whether there was a significant change from pre- to post-PTC intervention, a paired samples t-test was performed. A P-value < 0.05 was considered statistically significant. As a final step, demographic control variables were

entered into the model to help explain differences from pre- to post-intervention.

Once all variables were recoded, frequencies were computed and paired sample t-tests were conducted on all remaining questions in the analysis to observe changes in responses between pre- and post-PTC intervention. Of the 48 questions analyzed, caregivers' (n=409)

scores significantly improved in 43 of them post-PTC, an amelioration approaching 90%. Because change scores were both in the positive and negative directions, two-tailed tests were used to evaluate whether or not the mean change was significant. Interpretation of Cohen's *d* indicates a moderate effect size with an *r* value of 0.34 and power over 0.60.

Table 1. Participant characteristics

Variable	N
Gender	
Male	60
Female	349
Ethnicity	
White	377
Asian	1
Native American	1
African	21
Hispanic	2
Education	
K-8	1
9-11	6
High school	67
Some college	98
College grad	126
Course work	109
Employment	
Full time	107
Part time	57
Not working	242
Income	
\$5000	4
\$10000	4
\$15000	16
\$20000	24
More than \$20000	329

Frequencies of group characteristics for participating men and women family caregivers

Table 2. Self-Care Behaviors

Behavior	Pre-PTC	Post-PTC	SE
Total time (hours) spent performing stress management or relaxation techniques 30-60 minutes (per week)	13.9	28.9*	0.08

*Post-PTC values were significantly different than pre-PTC values, $P = 0.001$. Mean hours (SE) spent by respondents performing self-care behaviours pre and post PTC. * $P = 0.001$

Table 3. Self-Care Behaviors

Behavior	Pre-PTC (Frequency)	Post-PTC (Frequency)
Put off going to the doctor	101	53*
Postponed getting regular checkups or exams	97	48*
Cancelled or missed medical appointments	69	28*

*Post-PTC values were significantly different than pre-PTC values, $P = 0.001$. Frequencies of total respondents performing self-care behaviours pre and post PTC. * $P = 0.001$

Results

Powerful tools for caregiver's weekly schedule topics covered in the six weekly PTC classes and were include as follow: Mean (SD) of group characteristics for participating men and women family caregivers.

Of the 1,038 total caregivers whose data were collected, 409 completed both the pre-PTC and post-PTC questionnaires. Subjects' ages 64.7 (11.4) and gender diversity (female=349, male=60) were typical of average American middle-aged adult caregivers. No subjects reported any significant changes to their health during the course of the study.

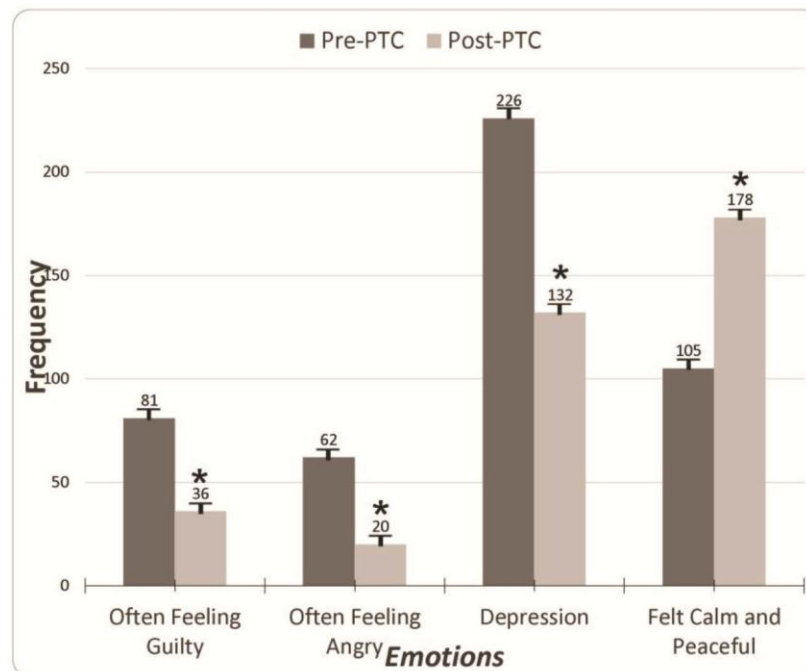
After six weeks of Powerful Tools classes, caregivers showed an increase in their total time spent performing stress management or relaxation techniques (Table 2). The greatest increase was in the category from less than 30 minutes per week (57 caregivers) to between 30-60 minutes per week (118 caregivers); ($t(409) = -7.322, P = 0.001$). There was a 12% decrease in both the percentage of caregivers who did not put off going to the doctor (101 caregivers before PTC to 53 caregivers after PTC) ($t(409) = 4.563, P = 0.001$) and who did not postpone regular checkups or exams pre and post PTC (97 to 48 caregivers) ($t(409) = 4.739, P = 0.001$). There was also a 10% decline in caregivers who did not cancel or miss their medical appointments (69 caregivers before PTC to 28 caregivers after PTC) ($t(409) = 4.553, P = 0.001$) (Table 3).

Following Powerful Tools, caregivers who reported often feeling guilty or angry both decreased by 11% (81 caregivers pre-PTC to 36 caregivers post-PTC), ($t(409) = 6.487, P = 0.001$) and 10% (62 caregivers pre-PTC to 20 caregivers post-PTC), ($t(409) = 7.513, P = 0.001$), respectively. The percentage of caregivers who reported feeling depressed decreased by over 23% (226 caregivers pre-PTC to 132 caregivers post-PTC), ($t(409) = 6.990, P = 0.001$). Furthermore, caregivers who often felt calm and peaceful increased after PTC by approximately 17% (105 caregivers pre-PTC to 178 caregivers post-PTC), ($t(409) = -5.118, P = 0.001$) (Figure 1).

After completing the Powerful Tools course, caregivers increased their confidence in coping with the stress of caregiving (Figure 2). Prior to PTC, approximately 22% (90) of caregivers reported no confidence at all, while after PTC less than 3% (12) of caregivers reported lacking confidence ($t(409) = -15.303, P = 0.001$). Conversely, those reporting total confidence increased by 35% (88 caregivers pre-PTC to 234 caregivers post-PTC), ($t(409) = -14.304, P = 0.001$). Furthermore, caregivers who reported a lack of confidence in dealing with an increase in the care needs of their recipient dropped from nearly 33% (137) to less than 5% (19), ($t(409) = -14.755, P = 0.001$), while those saying they felt completely confident increased from 90 pre-PTC to 233 post-PTC ($t(409) = -8.039, P < 0.05$). Following Powerful Tools, caregivers increased their usage of community resources. Getting help with daily tasks (e.g. housecleaning, yard work, shopping, cooking, transportation) increased by 16% (142 caregivers pre-PTC to 208 caregivers post-PTC), ($t(409) = -8.039, P = 0.001$). Discussing their needs and concerns related to caregiving with facility staff increased by 26% (192 caregivers pre-PTC to 286 caregivers post-PTC), ($t(409) = -10.679, P = 0.001$). Discussing their concerns with their doctors increased by 23% (191 caregivers pre-PTC to 287 caregivers post-PTC), ($t(409) = -10.237, P = 0.001$), with their family members increased by 23% (140 caregivers pre-PTC to 235 caregivers post-PTC), ($t(409) = -10.351, P = 0.001$), and with their friends increased by 20% (176 caregivers pre-PTC to 256 caregivers post-PTC), ($t(409) = -9.624, P = 0.001$) (Figure 3).

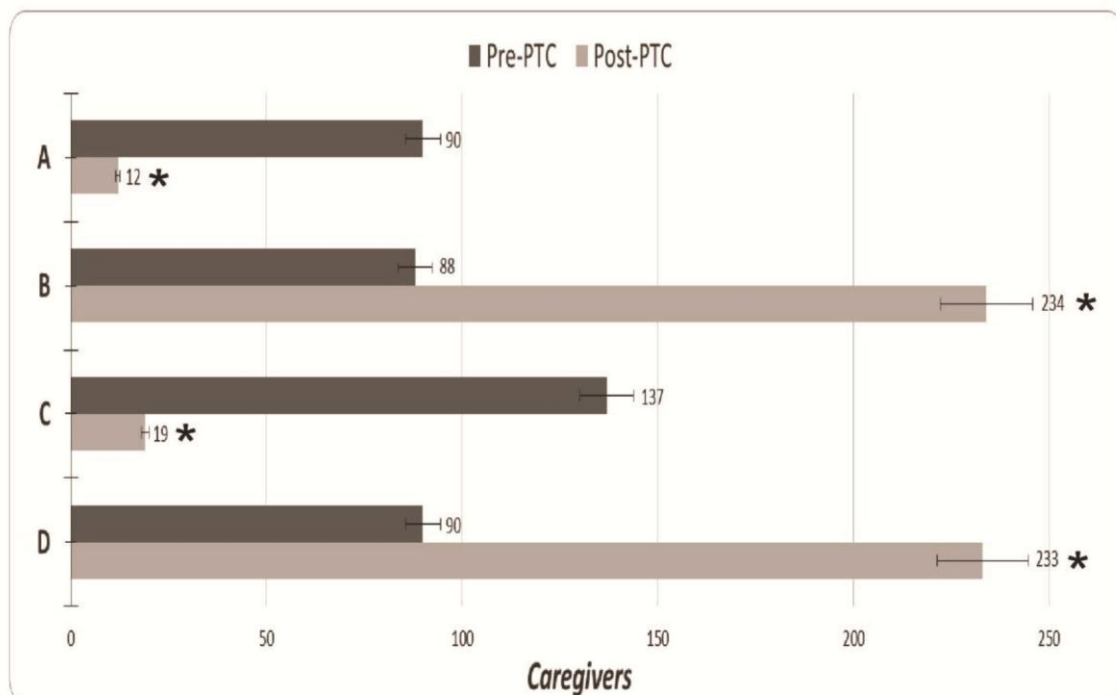
Discussion

The purpose of this analysis was to measure any changes in caregiver self-care behaviors, self-efficacy, management of emotions, and in the use of community resources after a 6-week psychoeducational course entitled Powerful Tools for Caregivers (PTC) as compared to before course enrollment. Caregivers reported spending more time conducting stress management and relaxation techniques



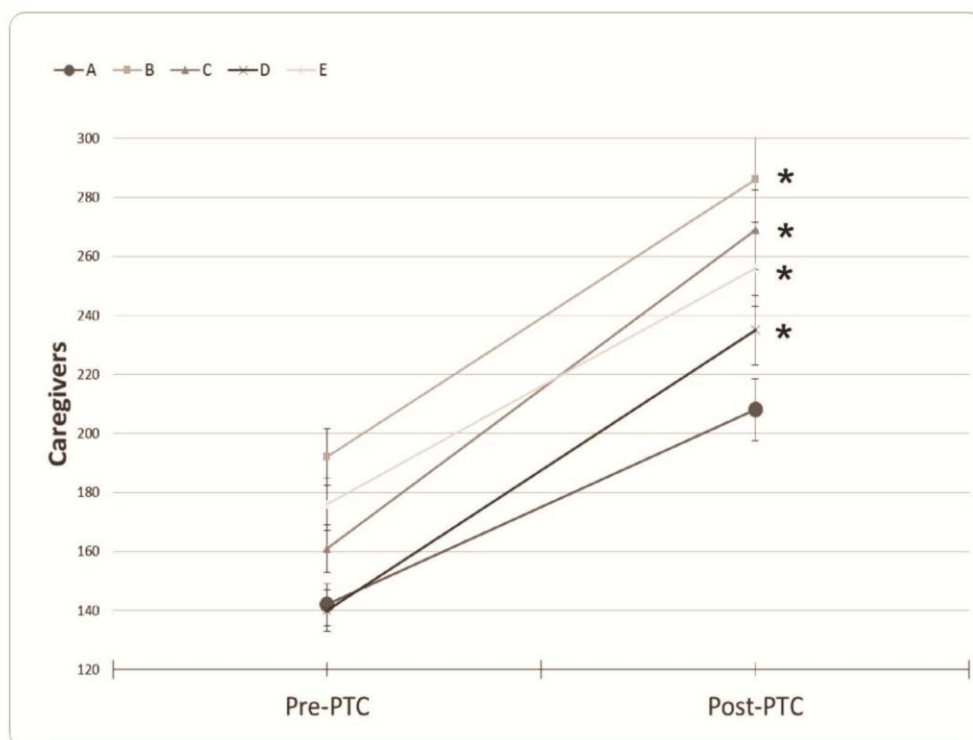
Frequency of caregivers who reported feelings of guilt, anger, depression, or peacefulness pre and post PTC. *P = 0.001, Management of Emotions before and after Powerful Tools for Caregivers. Paired t-tests were performed on values between time points. Error bars represent standard errors. *Post-PTC values were significantly different than pre-PTC values, P = 0.001.

Figure 1. Management of emotions



Frequency of caregivers who reported confidence in coping with the stress of caregiving pre and post PTC. *P = 0.001. Paired t-tests were performed on values between time points. Error bars represent standard errors. * Post-PTC values were significantly different than pre-PTC values, P = 0.001. **A** No Confidence in Coping with Stress of Caregiving, **B** Total Confidence in Coping with Stress of Caregiving, **C** Lack of Confidence in Dealing with an Increase in Necessary Care, **D** Complete Confidence in Dealing with an Increase in Necessary Care

Figure 2. Self-Efficacy before and after powerful tools for caregivers



Frequency of caregivers who reported utilizing various community resources pre and post PTC. * $p = 0.001$, Community Resource Usage pre and post Powerful Tools for Caregivers. Paired t-tests were performed on values between time points. Error bars represent standard errors. * Post-PTC values were significantly different than pre-PTC values, $p = 0.001$. **A** Obtaining help with daily tasks, **B** Discussing caregiving needs/concerns with doctors, **C** Discussing caregiving needs/concerns with facility staff, **D** Discussing caregiving needs/concerns with family, **E** Discussing caregiving needs/concerns with friends

Figure 3. Use of community resources

post-PTC. Caregivers also reported cancelling fewer of their own medical appointments and receiving more regular checkups and exams than pre-PTC.

Caregivers further described spending less time feeling depressed, guilty or angry, while instead experiencing more periods of calm and peacefulness, after completing PTC. These findings suggest that the Powerful Tools course results in caregivers who take better care of themselves, who react to their emotions in a healthier manner, who are more confident in their caregiving abilities as well as coping with the demands of caregiving, and who are more knowledgeable about receiving assistance from their community when necessary. These results are in agreement with Cooper and colleagues who demonstrated that psychoeducational strategies which combine caregiving skill

building with stress management and coping skill development have shown a positive effect on caregiver scores of anger, hostility, anxiety and depression.⁴

Additionally, Holland *et al.*, described caregivers with high intensity caregiving situations tended to have less adaptive cortisol patterns, and these 'at-risk' caregivers benefited most from a psychoeducational intervention, having more normal cortisol patterns at post-treatment.⁵ An intervention by Hepburn *et al.*, consisted of a 14-hour training program in seven weekly 2-hour sessions based on the stress and coping theory.⁶ Three months after the study ended, those in the intervention group experienced lower burden and were less depressed ($P = 0.04$) than those in the control group. Coon's group also found that depression ($P = 0.02$) and self-efficacy ($P = 0.03$) both improved in

caregivers immediately and at 3 months following structured small group training of anger or depression management in a 2-hr workshop format, for 8 consecutive weeks.⁷ These results correspond with those found in caregivers immediately after completing the PTC program, although longitudinal PTC follow-up was not administered. These data are consistent with a growing body of evidence supporting the efficacy of skills training to improve both the type of coping strategies used by caregivers, as well as their affective states. Collectively, psychoeducational programs such as PTC have shown to be an effective intervention for caregiver depression, burden, and distress.

Some components of the PTC questionnaire not extensively investigated in other studies involving caregivers were health changes specifically related to diet and physical activity. A healthy diet can be a key lifestyle behavior to reduce stress, and those living with chronic stress have been shown to have elevated susceptibility to poor nutrition and diminished appetite.⁸ The central hormonal effects of stress through corticotropin-releasing hormone (CRH) in the hypothalamic-pituitary-adrenal (HPA) axis may decrease food intake as has been shown in experimental animals by intracerebroventricular injection of CRH.⁹ Interestingly, it has been reported that chronic stress can also lead to increased food intake¹⁰ and may predict relapse and overeating after weight loss achieved by hypocaloric dieting in women.¹¹ Thus, exposure to chronic stress has been shown to both increase the consumption of calorically-dense, high-fat foods (and therefore the risk of obesity) as well as lead to stress-induced anorexia.¹² This is important to the chronically stressed caregiver as they may find themselves increasingly consuming high calorie "comfort" foods, or not having the time to cook and eat sufficient quantities of nutritious foods. In the present study, approximately half of the caregivers (n=187)

reported eating poorly prior to the PTC course, with no significant improvement after PTC. In addition, another important intervention to reduce the effects of chronic fatigue and depression is increased physical activity. It has been reported that lower levels of physical activity increase the risk of cardiovascular disease,¹³ hypertension,¹⁴ cancer,¹⁵ type 2 diabetes,¹⁵ and depression.¹⁶

Additionally, people with high physical activity have better quality of sleep than those with low physical activity.¹⁷ This is notable given that family caregivers as a group tend to suffer from poor sleep patterns.¹⁸ Moreover, the mortality rate of sedentary individuals is higher than that of physically active individuals.¹⁹ Taken together, the physical health and psychological well-being of caregivers is at increased risk due to their reduced opportunities for regular exercise.

The American College of Sports Medicine (ACSM) recommends that most adults engage in moderate-intensity cardiorespiratory exercise training for $\geq 30 \text{ min} \cdot \text{d}^{-1}$ on $\geq 5 \text{ d} \cdot \text{wk}^{-1}$ for a total of $\geq 150 \text{ min} \cdot \text{wk}^{-1}$.²⁰ This amount of exercise is also recommended for older adults (50 years old and older) in another ACSM Position Stand.²¹ In the present analysis, caregivers reported no significant increase in the amount of time they spent exercising (e.g. strength training, stretching, walking, bicycling) (38.1% - 40.8%, $P = 0.196$) in the ACSM recommended "1 to 3 hours per week" category after completing the Powerful Tools program.

This is in agreement with Wilcox²² who demonstrated that caregivers take part in limited leisure time physical activities. Given that caregivers in the present study reported eating poorly with no improvement in exercise, it is unfortunate that no data were collected on caregiver dietary intake, Body Mass Index (BMI), body weight, or percent body fat. In aggregate, these findings suggest that the PTC program may benefit from training sessions that place additional emphasis on

caregiver physical fitness and nutritional intake.

While studies that investigate home-based moderate intensity physical activity have shown decreased caregiver burden,^{23,24} another study using a similar paradigm but with exercise performed away from the home revealed negative effects on caregivers' sense of burden.²⁵ This may be due to the specific stress associated with their caregiving role remaining fundamentally unchanged upon returning home from exercising. Indeed, the accompanying stress experienced after leaving a care recipient at home to go participate in a physical fitness program may increase overall burden and feelings of guilt within the itinerant caregiver. Consequently, caregivers may benefit more profoundly by exercise interventions which are designed for within-the-home performance so as to prevent unwanted separation between care providers from their care recipients and thereby ameliorating stress and burden.

A caregiver's stress is best described as a multidimensional problem.²⁶ Well-being results from the dynamic interplay of multiple stressors and the resources that are available to mediate them.²⁷ Stressors vary considerably over time and from one caregiver to the next. Indeed, a limitation of the current study is that since this was a meta-analysis, there was no opportunity for caregiver/researcher interaction to investigate further the stressors adversely affecting individual caregivers. However, multidimensional group interventions such as PTC have been found to be more effective than individual treatments in addressing caregiver stress.²⁸ A group setting such as PTC may provide an opportunity for participants to exchange ideas and strategies for coping with their shared difficulties, thus enabling mutual learning. Moreover, previous studies have shown that interventions in groups have the added advantage of constructing supportive social networks.²⁹ consequently,

it may be that multidimensional, and group interventions are more effective than one-dimensional, individual programs because they are more likely to address a particular caregiver's problems. Indeed, many of the most successful caregiver interventions are multidimensional, addressing multiple stressors affecting caregivers' health and well-being.³⁰⁻³³ In contrast, use of a single intervention or service is often less effective at lowering stress or burden.

Schulz *et al.*, led a multi-site randomized clinical trial, Resources for Enhancing Alzheimer's Caregiver Health (REACH), involving 1,222 caregivers and care recipients.³⁴ The REACH investigators studied several different multidimensional interventions that included pre-planned meta-analyses aimed at assessing the relative impact of different interventions across multiple sites. REACH findings demonstrated that certain subgroups of caregivers benefitted from the interventions more than others. While we did not see differences in this PTC investigation, Schulz *et al.*, reported REACH caregivers with a high school education or less responded more favorably, as did female caregivers compared to male caregivers.

Multidimensional interventions have also been shown to be more readily accepted across ethnic and cultural groups.³⁵ Hence, interventions may need to be tailored to the specific needs and background of individual caregivers in order to maximize assistance.

Researchers and clinicians have devised an assortment of methods in an effort to reduce the adverse consequences of caregiving through education and training programs, support groups, and counseling. Successful interventions have been reported to reduce caregiver depression, distress, and psychological morbidity; delay care recipients' admission to nursing homes; and improve care recipients' psychological well-being. The literature also contains a range of methods for delivering caregiver interventions. Among these are traditional

approaches such as individual and group therapy sessions. More recently, modern technologies involving enhanced telecommunication systems,³⁶ instructional DVDs,³⁷ and wireless internet-connected computers³⁸ have been employed. As innovative tools become easier to use and more readily available, caregiver treatment delivery options will assuredly increase.

Likewise, the literature reveals there is no distinct, easily implemented, and consistently effective method for achieving clinically significant outcomes in all caregivers. Knight and colleagues suggested that a one-size-fits-all approach to supporting caregivers may not be useful because caregivers have a diverse array of needs.³⁹ Indeed, dementia caregiving is highly demanding. Furthermore, it cannot be assumed that the same intervention will work among caregivers of different backgrounds and cultures.³⁹

The current study had limitations both in research design and data collection. The specific limitations are concerning the lack of a control group, confounding variables, and its sample size.

One of the limitations was the lack of a control group. Future studies should include participants enrolled in both a program similar to PTC, and another group not enrolled in any skill-building program whatsoever. Such a design would allow for better statistical modeling and greater inferential power.

Although analysis showed improvements in various measures after 6 weeks of PTC, all results must be interpreted with caution. Attempts were made to account for and document confounding variables. Yet both adverse and beneficial events in participants' personal lives had the potential to affect their stress levels, questionnaire responses, and test performances. While participants were asked to report anything out of the ordinary and to keep their daily schedules routine, there is still a chance outside factors could have influenced results. Future studies

could include more testing and questionnaires beyond simply at the pre and post-study time-points, thereby providing researchers with a more complete picture throughout the course of the study.

The limited number of participants must also be considered, specifically regarding external validity. A larger sample size may well have resulted in different outcomes, and thus generalizing these findings to heterogeneous caregiving populations at large is not feasible. Looking ahead, larger studies should now be performed to further investigate the current findings.

As the number of individuals with dementia increases, so too will the number of caregivers. The need for physical activity and dietary interventions in the caregiving population is exhibited by their low levels of exercise, poor nutritional intake, significantly greater stress, anxiety, depression and deleterious physical condition. Consequently, it is imperative that interventions are developed with specific strategies for overcoming the recognized exercise barriers and underlying dietary obstacles to improve the aggregate health and quality of life of family caregivers. Logically, caregivers with compromised physical and emotional welfare are less likely to provide quality care due to their own ailing health.

Therefore, the institutionalization of elderly care recipients could potentially be delayed when more active, healthier and less despondent providers administer that care.

Future Studies most interventions report some level of success, and as a group provide valuable insight regarding different approaches for achieving positive results.

Strong consensus exists that all caregivers are likely to benefit from enhanced knowledge about their caregiving role, the care recipient's disease and locally available resources, as well as training in general problem-solving and behavior management skills or caregivers' emotional response to caregiving. Once these needs have been

met, future studies should examine how home-bound caregivers may additionally benefit from interventions that focus on physical fitness, nutrition, and overall mind and body health.

Conclusion

Powerful Tools for Caregivers had positive effects on caregivers' self-care behaviors, self-efficacy, management of emotions, and in the use of community resources.

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Ethical issues

None to be declared.

Conflict of interest

The authors declare no conflict of interest in this study.

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