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Community-based "powerful tools" intervention enhances health of caregivers

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Abstract

Family caregiving is prevalent and may have adverse impacts on health, particularly for elder caregivers who tend to have chronic health conditions which need ongoing self-management. Interventions that empower family caregivers to take care of themselves are needed. This study examined the impact on caregivers of participation in a self-care skill-building, self-efficacy enhancing, community-based program called powerful tools for caregiving (PTC). We assessed health-risk behaviors, self-care, and psychological well-being among 118 adult caregivers who participated in PTC in western Washington state between July 2001 and June 2004, about half of whom were aged 65 or older. Health-risk behaviors were reduced and self-care and psychological well-being improved significantly, overall and for each stratum of age (≥ 65 years of age vs. <65).

Keywords

self-care; health behavior; caregivers; self efficacy; intervention studies; community dwelling elderly

1. Introduction

Family caregiving, meaning informal, unpaid care provided by family, neighbors, or friends to older adults residing in the community, is prevalent in the United States. Nearly one in four households is involved in giving care to an adult aged 50+ (AARP, 2004). Older adults are often the ones providing such care: Nearly half of all family caregivers are aged sixty-five or older (Mack et al., 2005). With the aging of our population, the number of older adults assuming caregiving roles is likely to grow.

Family caregiving has been linked with a variety of problems, including self-care neglect, depression, social isolation, and mortality (Donelan et al., 2002; Hirst, 2005; Robinson et al., 2005; Yeung et al., 2007). Older caregivers are a particularly vulnerable caregiver subgroup,

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because caregiving responsibilities may lead them to neglect their own health issues at an age when they are likely to have one or more chronic conditions requiring ongoing self-care and medical monitoring (McGarry et al., 2001;Bodenheimer et al., 2002; Katbamna et al., 2002; Navaie-Waliser et al., 2002; Crankshaw et al., 2003). For example, caregivers may find it challenging to engage in any form of physical activity on a regular basis, even though regular physical activity has been shown to have important physical as well as mental health benefits (Warburton et al., 2006). Thus, interventions are needed to help older caregivers maintain their own health and a healthy lifestyle while engaged in caregiving (McCann et al., 2004).

One such intervention, the PTC program, holds promise for empowering family caregivers to maintain their own health. Based on the chronic disease self-management program (CDSMP) (Lorig et al., 1999; Lorig et al., 2001a,b; Lorig and Holman, 2003), PTC is designed to enhance self-efficacy for informal caregiving, including self-care, through learning a new set of skills or "tools." PTC has been implemented in a variety of community settings across the United States. However, published reports of the program's impacts on caregivers' health are scarce (Kuhn et al., 2003; Boise et al., 2005), and none has examined the impact of the program on the health of older caregivers. Data collected from participants in PTC programs in the Puget Sound region of Washington state provided the opportunity to examine the impact of this program on caregivers' self-care (e.g., exercise, stress management or relaxation techniques), health-risk behaviors that could lead to physical health problems, and psychological wellbeing, and information on participants' age allowed us to examine these outcomes according to age. We hypothesized that, after participating in the PTC program, caregivers would engage in fewer health-risk behaviors and improve in self-care and psychological well-being, and that these effects would be present regardless of age of the caregiver.

2. Methods

2.1. Setting

The PTC program is offered in a variety of venues throughout western Washington state, such as senior centers, senior apartments, church halls, and public libraries. The Washington state Aging and Adult (formerly Disability) Services Administration provides financial support for the program. This study reports on data collected from twelve venues in King and Snohomish counties.

2.2. Participants

Family caregivers joined PTC workshops by responding to announcements at senior centers and in community newspapers or at the recommendation of senior center social workers.

2.3. Data collection

Data were collected via written questionnaires completed by each participant before the start of their first PTC session and again after the sixth (final) session. Each community setting that offered PTC submitted data to the offices of Senior Services of Seattle/King county, whereafter data were coded and entered into a computerized format. The final data file was de-identified and made available to researchers at the University of Washington. Researchers were not involved in PTC training or program implementation. The University of Washington Institutional Review Board approved the research, including data acquisition and analysis.

2.4. Description of variables

2.4.1. Caregiver and care recipient characteristics—Demographic characteristics of the caregiver, nature of care provided, and health conditions of the care recipient were elicited by a written questionnaire. Personal care was defined as assistance with bathing, dressing, or

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other self-care activity, with three response options (not at all, some days but not every day, or daily/almost daily). The number of chronic conditions of the care recipient was determined by summing across six major disease categories (Alzheimer's disease or other dementia, cancer, diabetes, heart disease, Parkinson's disease or other movement disorder, and stroke) along with a seventh category created to cover write-in responses that represented conditions with implications for physical functioning and caregiving (e.g., macular degeneration, chronic lung disease).

2.4.2. Health-related outcome variables—Outcomes were assessed by comparing responses on pretest and posttest questionnaires. Health-risk behaviors were determined via six items similar to those used in the Resources for enhancing Alzheimer's caregiver health (REACH) project (Schulz et al., 2001, 2003) and three additional items, all with dichotomous (yes/no) responses. These behaviors included (1) putting off going to the doctor, (2) failing to stay in bed when ill, (3) postponing getting regular checkups or exams, (4) canceling or missing medical appointments, (5) failing to get enough rest, (6) taking medications improperly (too little, too much, not at all), (7) failing to get enough exercise, (8) eating poorly, and (9) putting off recreational activities you enjoy. The sum of "yes" responses for these items ranged from zero to nine, with higher scores indicating that the participant engaged in a greater number of health-risk behaviors.

Time spent on physical exercise and stress management or relaxation techniques were investigated as markers of self-care with two questions: "During the past week, how much total time did you spend exercising/practicing relaxation techniques?" Each question had five response options (0=none, 1=less than 30 minutes, 2=30 to 60 minutes, 3=1 to 3 hours, or 4=more than 3 hours) (Lorig et al., 1996).

The mental health index-5 (MHI-5) (Berwick et al., 1991) was used to assess psychological well-being: Have you ... (1) been a very nervous person, (2) felt downhearted and blue, (3) felt so down in the dumps that nothing could cheer you up, (4) felt calm and peaceful, and (5) been a happy person. Participants rated each item on a four-point scale scored zero to three (never, sometimes, often, or always). Negatively worded items (one, two, and three) were reverse-scored, such that the total score ranged from zero to fifteen, with higher scores indicating better psychological well-being.

2.5. Statistical analysis

Differences on demographic and health-related measures between caregivers who did or did not complete the posttest questionnaire were assessed using the Student t-test or the Mann-Whitney U test (for data not normally distributed) for continuous variables and chi-square tests for categorical data.

Change from baseline (pretest to posttest) on health-risk behaviors, self-care, and psychological well-being was assessed using the Wilcoxon Signed Rank test for continuous variables and McNemar's test for matched pairs for categorical variables, first for all participants together and then stratified by caregiver age (age ≥ 65 vs. age < 65). Degree of change in health-risk behavior and psychological well-being according to caregiver age was assessed using the Mann-Whitney U test.

Multivariate linear regression analysis was used to identify independent correlates of change in number of health-risk behaviors and in psychological well-being. Logical groupings (also referred to as family models) (Kleinbaum et al., 1988) of related variables (i.e., caregiver demographics; care recipient characteristics; caregiver/care recipient dyad characteristics) were entered together into linear regression models using the Statistical Package for the Social

Sciences, version 12.0 for Windows (SPSS, Inc., Chicago, Illinois). Variables that were at least marginally significant (P < 0.10) in each family model were entered into the final model.

3. Theory

PTC is a community-based, group psychoeducational program based on social learning theory (Bandura, 1977, 2004; Rimal, 2000) and modeled after the CDSMP (Lorig et al., 1999, 2001a). PTC was developed in the 1990s by Legacy Health System, a nonprofit healthcare corporation serving the Portland, Oregon area, to improve self-care and well-being among informal caregivers. PTC was developed initially for caregivers of people with Alzheimer's disease, Parkinson's disease, and stroke but appears to be equally effective for other caregivers (Kuhn et al., 2003). Excerpts from the PTC companion text Caregiver Helpbook (Schmall et al., 2000) are available online at the Family Caregiver Alliance website (www.caregiver.org/caregiver/jsp/).

The PTC program is presented in a series of six sessions, each held for two and one-half hours once a week, in a small group setting. The scripted curriculum is presented by a team comprised of one professional (e.g., social worker, nurse) and one peer/volunteer leader trained in PTC group leadership by master trainers. Topics for the six sessions are: Taking care of you, identifying and reducing personal stress, communicating feelings, needs, and concerns, communicating in challenging situations, learning from our emotions, and mastering caregiving decisions. Each PTC session uses brainstorming, role-play, and other methods to teach "tools" that empower caregivers to manage stress, improve communication, avoid negative emotions, and make difficult caregiving decisions. PTC also uses experiential learning to increase the likelihood of actually using the tools.

PTC's curriculum includes all four elements typical of effective psychoeducational support groups: Education, emotion-focused coping strategies, problem-solving coping strategies, and support (Toseland et al., 2001). PTC also includes essential components of CDSMP, including skills mastery, reinterpretation of symptoms, modeling, and social persuasion to enhance a sense of personal efficacy. These components are conveyed through group activities such as guided learning or practice in using tools through weekly group review and encouragement of individual "action plans," modeling self-management behaviors and problem-solving strategies, and social persuasion through group support and guidance for individual self-management efforts (Lorig et al., 2001a).

Through participation in the PTC program, caregivers learn and practice self-care skills ("tools") that enable them to take care of themselves while managing their caregiving responsibilities; in this sense, these are impressive (or "powerful") tools; a limited body of evidence supports the putative power of these tools (Kuhn et al., 2003; Boise et al., 2005).

4. Results

4.1. Participant characteristics

Between July 2001 and June 2004, 208 family caregivers participated in the PTC program in western Washington and filled out a questionnaire. Forty-three of the 208 participants (21%) were missing key variables, such as age, and so were excluded from the analyses. A total of 165 (79%) caregivers completed a questionnaire at enrollment; of those, 118 (72%) also completed a posttest questionnaire. Table 1 shows characteristics of caregivers who completed pretest questionnaires, comparing those who completed posttest questionnaires (N=118) with those who did not (N=47). No differences between these groups were significant for any demographic or health-related measure.

Table 1 also provides descriptive information about the 118 caregivers who completed both pretest and posttest questionnaires. Forty-six (39%) were aged 65 years or older (data not shown), 91% were female, 92% were white, 59% were living together with the care recipient, and 24% were giving personal care to the care recipient daily or almost daily. About 42% of caregivers reported being the spouse of their care recipient, and 39% reported being an adult child of the care recipient. Three quarters of caregivers aged 65 or older were spouses of the care recipient, whereas only 20% of caregivers younger than 65 were spouses (data not shown). The most common condition among care recipients was dementia, followed by heart disease and stroke. The mean MHI-5 score of nine (out of a total of fifteen points) is equivalent to a score of 60 on a 100 point scale, where 100 represents optimum mental health (Berwick et al., 1991); thus, these participants were at or near the cut-point of \leq 60 proposed by others as suggestive of a mood disorder (Rumpf et al., 2001). For comparison, the general Dutch population of adults aged 18 years or older averaged 80 on a 100 point scale (Hoeymans et al., 2004).

4.2. Adherence to the PTC program

Attendance for the 118 who completed questionnaires at both time points was as follows: Four participants (3%) attended three of the six sessions; twenty-five (21%) attended four sessions; thirty-one (26%) attended five sessions; and fifty-eight (49%) attended all six sessions. The number of sessions attended had no effect on outcomes.

4.3. Health-related outcomes overall and according to category of caregiver age

Table 2 shows health-related outcomes for the group as a whole and by age category (<65 vs. \geq 65 years). Health-risk behaviors, self-care, and psychological well-being all improved, both for the group overall and for each stratum of age. Improvements were statistically significant for all measures except for "time for stress management or relaxation techniques." We examined each health risk behavior individually and observed significant changes in the direction of reduction in the risk behavior from pretest to posttest for all behaviors except "failing to stay in bed when ill" and "canceling or missing medical appointments." As shown in Table 2, caregivers aged 65+ exhibited less reduction in health-risk behavior than those under age 65 (mean score change for those aged 65+ = -0.7 points vs. -1.5 points for those <65 years; Mann Whitney U *P*=0.029) and had less improvement in psychological well-being than the younger subgroup (mean score change = +1.1 points vs. +1.9 points; Mann Whitney U *P*=0.008).

4.4. Correlates of change in health-risk behavior and psychological well-being

When factors that might be correlated with change in number of health-risk behaviors and psychological well-being score from pre- to posttest were examined in partial, or family models, three factors were at least marginally associated with change in health-risk behavior: Age \geq 65 years, being a spouse caregiver, and number of conditions in the care recipient. As shown in Table 3, in the final multivariate model containing these three factors, only the number of care recipient conditions remained associated with change in caregiver health-risk behavior. The inverse relationship observed indicates that, as the number of care recipient conditions increased, the change in number of caregiver health-risk behaviors decreased. In the partial (family) models examining associations with change in psychological well-being, being a college graduate and living with the care recipient were marginally associated with this outcome. In the final multivariate model containing these two factors, being a college graduate was associated with greater improvement in psychological well-being; living with the care recipient was of borderline significance (Table 3).

5. Discussion

This study found significant reduction in health-risk behaviors and improvement in self-care and psychological well-being after PTC participation. The degree of improvement appeared to be greater among participants younger than 65 years. Multivariate models suggested that the care recipients' burden of illness was an important factor related to reduction in caregiver health-risk behaviors, and that a college education was associated with improvement in psychological well-being. The fact that our final multivariate model showed no significant association between being aged 65 or older and reduction in health-risk behavior or improvement in psychological well-being suggests that age is not a substantial determinant of PTC's effectiveness; this finding is compatible with the bivariate results showing improvements in health-related outcomes for both older and younger caregivers. To our knowledge, ours is the first study to examine the effects of PTC by age of the caregiver.

Studies with PTC participants in other regions of the United States have also found significant reduction in health-risk behavior and improvement in self-care and psychological well-being (Kuhn et al., 2003; Boise et al., 2005). One report (Kuhn et al., 2003) assessed PTC benefits according to the caregiver's relationship to the care recipient but not according to caregiver age.

Interestingly, change in health-risk behavior was inversely correlated with the number of care recipient conditions, which is a good index of overall health burden (Perkins et al., 2002). Other studies have shown that caregiver interventions have more modest benefits for caregivers of individuals with dementia than for other caregivers (Sorensen et al., 2002). Our results suggest that caregivers for individuals with multiple chronic conditions may derive less benefit from PTC; however, further research is needed in this area.

Others have found that older caregivers with higher educational attainment report higher life satisfaction and better physical health (Rose-Rego et al., 1998; Lee et al., 2001). A large literature has previously demonstrated an association between lower socioeconomic status and vulnerability to depression among caregivers, regardless of caregiver age (Kessler et al., 1985; Rose-Rego et al., 1998). Our study may be the first to report an association between higher educational attainment and improvement in psychological well-being among caregivers involved in a self-care skill-building, self-efficacy enhancing intervention.

Several strengths of this study merit mention. First, data were collected from a substantial number of PTC participants as part of routine community-based program activities. The PTC program is offered to the general public, so those who choose to participate are self-selected. The authors did not participate in or supervise the recruitment of program attendees, but simply analyzed the data that were collected from this real-world program (i.e., a program that is *not* being implemented as part of a research study) operating in western Washington state. Although this was a convenience sample, the average age of participants resembles the average age of informal caregivers nationally (62.7 years of age in 1999) (Mack et al., 2005). Additionally, participation bias is unlikely, because those who completed the posttest evaluation did not differ from those who did not complete it. Third, we have a high degree of confidence that program fidelity was maintained, because the same two highly experienced master trainers implemented the PTC intervention for almost all of the PTC workshops on which this report is based. Finally, attendance at all six PTC sessions by almost half (49%) the participants, and at five of six sessions by another 26%, indicates excellent adherence to the PTC program under real-world conditions. The small number (3%) who attended fewer than four sessions limits our ability to detect either a correlation or a threshold effect of attendance on health-related outcomes. Prior reports considered four sessions as "complete" participation (Kuhn et al., 2003; Boise et al., 2005).

Several limitations of this study should be noted, including the use of a convenience sample that was predominantly white and female; thus, these results may not be generalizable to other groups of caregivers. The present results, like previous studies of the PTC intervention, include no comparison with a control group of similar caregivers. Thus, it is possible that the results may be attributable to factors other than participation in the PTC program. In addition, because the majority of workshops were led by the same master trainers, we cannot determine whether similar findings would be obtained with a greater variety of taster trainers. Finally, the persistence of effects observed and likely downstream health benefits cannot be addressed by

PTC appears promising as an intervention that facilitates self-care by caregivers, regardless of age. Theoretical models (Bandura, 1977, 2004; Rimal, 2000) and data of others (Lorig et al., 1999, 2001a,b) predict that enhancing self-care and reducing health-risk behaviors will yield lasting improvements in health and reduction in health care costs. Enhancing self-care is particularly important for older caregivers, who are likely to have one or more chronic illnesses requiring ongoing self-management to prevent progressive deterioration (Bodenheimer et al., 2002). Healthier caregivers should be able to provide higher quality care and keep their family member at home for a longer time, thus improving quality of life and reducing costs for both members of the caregiver-care recipient dyad.

6. Conclusions

the present evaluation.

Informal caregivers report reduced health-risk behavior and improved self-care and psychological well-being after participating in the PTC intervention. Caregivers older and younger than age 65 derive substantial benefits. These improvements are likely to be associated with other desired effects, including reduction of health problems, disability, mortality risk, and healthcare utilization and costs (Lebowitz et al., 1997; Lorig et al., 2001a,b; Wagner et al., 2001; Hubert et al., 2002). However, randomized controlled trials that directly measure health status and health care utilization are needed to provide unequivocal evidence for the efficacy of PTC on these outcomes.

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Table 1

Demographic and health-related characteristics of caregivers at time of pretest, according to completion of posttest questionnaire

Caregiver characteristics	Noncompleters (N=47)	Completers (N=118)	Total (N=165)	P ^a
Age, mean±SD ^b	61.7±12.7	61.4±11.9	61.5±12.1	0.877
Female, %	87.2	90.7	89.7	0.573
White, %	89.1	92.3	91.4	0.105
\leq High school graduate, %	23.4	17.9	19.5	0.570
Not working, %	72.3	72.4	72.4	0.989
Income >\$20,000 per year, %	66.0	67.8	67.3	0.365
Live together with CR, % ^C	61.7	58.5	59.4	0.743
Give personal care to CR daily/almost daily, %	15.9	24.1	21.8	0.247
Time for exercise ≥ 1 hour/week, %	38.3	44.1	42.7	0.672
Time for relaxation techniques or stress management ≥ 1 hour/week, $\%$	31.9	23.7	25.8	0.452
	Noncompleters (N=47)	Completers (N=118)	Total (N=165)	P *
Health-risk behaviors, mean±SD	4.0± 2.4	3.5± 2.2	3.6± 2.2	0.147
Psychological well-being scale, mean±SD	8.4 ± 2.7	8.9 ± 2.6	8.8 ± 2.6	0.122
Relation to CR, %				
Spouse	42.6	42.3	42.4	
Offspring	44.7	39.0	40.6	0.142
Offspring-in-law	6.4	2.5	3.6	
Other	6.4	15.3	12.7	
Missing	0.0	0.8	0.6	
Care Recipient Conditions, % d				
Dementia	42.6	52.5	49.7	0.301
Stroke	14.9	21.2	19.4	0.393
Movement disorder	10.6	14.4	13.3	0.619
Diabetes mellitus	21.3	15.3	17.0	0.364
Heart disease	29.8	22.9	24.8	0.354
Cancer	8.5	11.0	10.3	0.781
Other <i>e</i>	21.3	24.6	23.6	0.691

 ^{a}P -value for difference between those who completed posttest and those who did not complete posttest questionnaire.

^bSD: standard deviation.

^cCR: care recipient.

 d Percents do not add to 100 because respondents were asked to select all that applied.

^eOther category, created from write-in responses, included the following conditions that have implications for physical functioning and therefore, caregiving: Musculoskeletal diseases (e.g., osteoarthritis), eye diseases (e.g., macular degeneration), central nervous system diseases (e.g., multiple sclerosis), depression, psychosis, end-stage renal disease, and chronic lung disease.

Table 2

Health-risk behaviors, self-care, and psychological well-being of caregiver participants before and after participation in the Powerful Tools for Caregiving program, by subgroup of age and for the group overall.

	Caregivers -	<65 Years of A	↓ge (n=72)	Caregivers	Caregivers <65 Years of Age (n=72) Caregivers ≥65 Years of Age (n=46) All Caregivers (n=118)	ge (n=46)	All Ca	tregivers (n=	=118)
	Pretest	Pretest Posttest	Ρ	Pretest	Posttest		Pretest	P Pretest Posttest	Ρ
Health-risk behaviors, mean±SD	3.7±2.2	2.2 ± 1.6	<.001	3.0 ± 1.9	2.3 ± 1.5	.001	3.5±2.2	.001 3.5±2.2 2.2±1.6 <0.001	<0.001
Time for exercise ≥ 1 hour per week, %	43.1	68.1	<.001	45.7	65.2	.035	44.1	60.9	<0.001
Time for stress management ≥ 1 hour per week, %	21.2	28.2	.332	27.9	39.5	.180	23.7	32.5	0.076
Psychological well-being, mean±SD	8.8 ± 2.8	10.7 ± 2.4	<.001	9.2 ± 2.0	10.3 ± 2.0	<.001	8.9 ± 2.6	10.5 ± 2.3	< 0.001

Table 3

Multivariate linear regression models of change in health-risk behavior and psychological well-being scores ^a

	Change in Number of Health-risk Behaviors (posttest - pretest) b		Change in Psychological Well-being Score (posttes pretest) ^c	
Caregiver Variable	Regression Coefficient	Р	Regression Coefficient	Р
Elderly (≥65 years)	0.672	0.099	_	—
Spouse	0.194	0.629	—	—
Number of care recipient conditions	-0.422	0.017	—	
Caregiver is college graduate or more	_	—	0.770	0.047
Caregiver lives with care recipient	_	—	-0.733	0.060

^aAll variables were entered simultaneously into the final multivariate model as 1=yes and 0=no, except the number of care recipient conditions.

 ${}^{b}\mathrm{R}^{2}=0.123$

 ${}^{c}R^{2}=0.06$