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## **EMPOWERING FAMILY CAREGIVERS: THE POWERFUL TOOLS FOR CAREGIVING PROGRAM**

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*“Powerful Tools for Caregiving” is an education program for family caregivers of older adults. Based on a self-efficacy model, the program empowers family caregivers to reduce negative effects of caregiving and*

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*to practice self-care. Through a train-the-trainer approach, professional and community volunteers were trained as class leaders and master trainers. This enabled the Powerful Tools for Caregiving program to reach family caregivers in geographically dispersed regions and underserved communities. The program was evaluated using preclass, post-class, and 6-month follow-up surveys. Class participants rated the classes very positively, reported high use of the tools taught during the series, and showed significant improvements in self-efficacy, emotional well-being, and self-care behaviors.*

Caring for an older relative or friend can be stressful and isolating (George & Gwyther, 1986), often leading to depression (Covinsky et al., 2003; Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, 1989) and negative health impacts (Schulz & Beach, 1999). Caregivers have been found to neglect their own health and self-care as they focus their energies and concerns on the person receiving care (Connell, 1994). Because of the ubiquitous nature of family caregiving and its potential impact, it is important to develop relevant, cost-effective educational programs that can be broadly disseminated. Powerful Tools for Caregiving (PTC) is a self-efficacy-based education program that was designed to train class leaders with a broad range of prior educational training and experience using a conceptually well-grounded and tested curriculum. Using a train-the-trainer approach, Powerful Tools for Caregiving has successfully served family caregivers throughout the state of Oregon, including caregivers in small towns and from diverse ethnic communities. To date, Legacy Caregiver Services in Portland, OR, which developed the Powerful Tools for Caregiving program, has trained over 200 class leaders and served over 1200 family caregivers in Oregon. These family caregivers reside in at least 30 of the 36 counties in Oregon, and represent caregivers from diverse ethnic groups, including Hispanic, Korean, Vietnamese, Chinese, and African American. With trained class leaders in 15 states, an estimated 10,000 caregivers have benefited from the Powerful Tools for Caregiving classes.

### **PROGRAM DESCRIPTION**

Powerful Tools for Caregiving is designed to be conducted in 2½ hour sessions, once a week, over a 6-week period. Each week's class covers a different topic and teaches "tools" that provide useful techniques for improving caregivers' emotions, self-care behaviors, and self-efficacy. Each class also includes a different relaxation tool, e.g., guided imagery, deep breathing, or "shoulder lift," so participants take away from the class a repertoire of relaxation techniques.

**Table 1. Powerful tools for caregiving curriculum**

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**Class #1: Taking care of you**

Challenges of caregiving and the importance of caregiver self-care are emphasized.  
Caregivers begin to make an individualized action plan for self-care every week.

**Class #2: Identifying and reducing personal stress**

Steps for effective stress management are presented. Tools to reduce stress are discussed, including simple relaxation activities.

**Class #3: Communicating feelings, needs, and concerns**

Participants learn how to communicate their feelings, needs, and concerns more effectively by using “I” messages. Through dramatizations, caregivers experience the impact of “you” messages. Progressive muscle relaxation is practiced.

**Class #4: Communicating in challenging situations**

Participants practice two communication tools—assertiveness and Aikido—which are helpful in difficult situations. Caregivers further learn how to set limits and another form of progressive muscle relaxation is practiced.

**Class #5: Learning from our Emotions**

Focus is on identifying constructive ways for dealing with difficult feelings—especially anger, guilt, and depression—and resources for professional help.

**Class #6: Mastering caregiving decisions**

Tools for dealing with internal emotional changes and for making tough decisions are discussed including a decision-making model, a family meeting, and “tools of optimism.” Caregivers acknowledge their accomplishments and develop a long-term action plan.

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Relaxation audiotapes used during classes are also available for purchase (at cost) if desired by class participants for home use. The 6-week curriculum is described in Table 1.

The curriculum is carefully scripted so that persons with limited or no group facilitation experience as—well as those with training experience—can successfully colead the classes. All classes are coled, which increases the confidence, reduces the preparation time for class leaders, and strengthens the impact of leader modeling for class participants. Class leaders (including professionals), however, are encouraged to have some family caregiving experience to ensure effective modeling by coleaders. Once class leaders have coled two Powerful Tools for Caregiving series, they may apply to become “Master Trainers;” that is, to be certified and licensed to train their own class leaders. In this way, the program is widely disseminated.

### **CONCEPTUAL FOUNDATION**

The Powerful Tools for Caregiving program is modeled in its curriculum, teaching methods, and dissemination after the Chronic Disease

Self-Management Program (CDSMP), a model patient education program based on the concept of self-efficacy developed by Kate Lorig and colleagues at the Patient Education Research Center at Stanford University. A self-efficacy conceptual framework is based on social learning theory (Bandura, 1977). According to Gonzalez et al. (Gonzalez, Lorig, & Goepfinger, 1990, p. 133), "Perceived self-efficacy refers to people's beliefs in their capabilities to mobilize the motivation, cognitive resources, and courses of action needed to meet given situational demands." Self-efficacy-based education is concerned not only with the skills one has, but also with the judgments of what one can do with the skills one possesses.

Important principles underlying the Powerful Tools for Caregiving program include these ideas: (a) persons experiencing the condition, in this case caregiving, can be effective class leaders; (b) group process is an important learning tool; (c) persons with limited teaching experience can be effective coleaders with well-designed and scripted teaching materials; and d) teaching techniques such as brainstorming, role-playing, and paired discussion allow for class participants to apply the concepts to their own caregiving situations and to learn from each other.

The curriculum utilizes four empirically-verified strategies for enhancing self-efficacy (Gonzalez, Lorig, & Goepfinger, 1990):

### ***Skills Mastery***

Learning, practicing, and experiencing success in helpful behaviors and practices are a key to gaining self-efficacy. One of the best ways to foster mastery is to have clients set goals for themselves. In the Powerful Tools for Caregiving, class participants are invited to develop an "action plan" each week. In this plan they identify something they want to do during the week, specify what they will do, when they will do it, how often and how much, and state their confidence in completing the plan. Class participants who have had difficulty in achieving their action plan are helped by other members of the class to consider ways to accomplish it or change it so they can be more successful. Through this process, class participants gain confidence in using this tool.

### ***Modeling***

Modeling in the Powerful Tools for Caregiving program is demonstrated through the use of lay coleaders, who describe effective

caregiving practices and model the use of the tools from their own experience, *as well* as by providing opportunities for *class members to help each other* in finding solutions to problems.

### ***Reinterpretation of Feelings and Attitudes about Caregiving***

One cannot change the fundamental nature of Alzheimer's disease or other chronic diseases of older adults. Caregivers can, however, shift their focus from the negative aspects of disease and frailty, and of their caregiving responsibilities, to an acceptance of the realities of their situation. Caregivers also gain enhanced appreciation of the importance and significant meaning their caregiving has—not only for the person they are caring for, but also for themselves. During the Powerful Tools for Caregiving classes, caregivers develop a sense of positive support from other class participants. Through sharing their feelings and experiences, they can carry these reinterpreted attitudes into their caregiving role.

### ***Persuasion***

Persuasion is a standard approach in health education, and it has its place in a self-efficacy model. Rather than relying on persuasion as the primary method for changing behavior, persuasion supplements the other three methods. Examples include urging caregivers to set slightly more ambitious goals than they might otherwise, or reporting on the evidence of the effectiveness of the techniques and tools taught during the classes.

## ***PROGRAM IMPLEMENTATION***

Funds from 3-year grants by the Robert Wood Johnson Foundation, Northwest Health Foundation, and Good Samaritan Foundation made it possible for Legacy Caregiver Services to disseminate PTC among rural and ethnic minority communities in Oregon. The funds also allowed translation of many of the program materials into Spanish, Korean, Chinese, and Vietnamese. The PTC program has proven to be culturally appropriate for the underserved rural and ethnic communities it serves—as long as cultural, language, economic, and literacy barriers are addressed. Bringing PTC to rural and ethnic communities requires a significant amount of time to develop relationships with community leaders, train class leaders, and develop translated program materials.

Legacy Caregiver Services widely advertised the availability of class-leader training sessions throughout the state. Experienced educators, service agency staff, and volunteers were encouraged to apply for the training program. Of the 200 plus class leaders trained in Oregon, approximately 1/3 were community volunteers, and 25% were from diverse ethnic communities. The paid leaders came from a variety of agencies and organizations, including hospitals, county aging services programs (Area Agencies on Aging), faith-based organizations (e.g., Parish Nurses), and County Extension programs.

Class leaders completed an intensive 4-day training program. The program was taught as a comprehensive whole, and leaders were discouraged from cutting out sections or reducing the number of class sessions. The training program includes directly experiencing the caregiver classes (as a caregiver), and training in how to be an effective class leader. Once class leaders had coled two Powerful Tools for Caregiving series, they were invited to apply to participate in a day-long training to become “Master Trainers”—that is, to be certified and licensed to train their own class leaders. Legacy Caregiver Services program staff supported Master Trainers as they prepared for and carried out their first class-leader training. In this way, the program was widely disseminated throughout Oregon. It continues to operate in many communities despite reduced grant funding at Legacy Caregiver Services.

### **PROGRAM EVALUATION**

The evaluation data reported here are for 33 classes conducted in Oregon during 2002 for which preclass, postclass, and 6-month follow-up evaluation forms were collected. Of the 359 persons who attended classes, 257 or 72%, completed the series (class participants were considered to have completed the series if they attended at least four classes). Outcomes for the classes were analyzed using paired *t* tests to compare the preclass and postclass measures. The *t* tests were also used to compare the preclass and 6-month follow-up measures for individuals who completed the class series. Of class completers, 226 returned preclass forms, and 204 completed postclass forms. A total of 186 class completers submitted both preclass and postclass evaluation forms, providing a 72% response rate for the postclass analysis. A 6-month evaluation was mailed to class completers, of whom 69 returned both the preclass and follow-up form. This provided a 27% response rate for the follow-up analysis.

### ***Data Collection***

The preclass survey instrument gathered demographic and caregiving characteristics for class participants. It also obtained characteristics of the persons the class participants were caring for. To assess satisfaction with the program, class participants were asked in the postclass survey (collected at the end of the final class) to rate each of the six classes in the series on a scale of 1 (poor) to 10 (excellent), and to also rate the series overall. They were also asked to report how they liked the class materials, and whether or not they used the tools taught during the classes (asked in both the postclass and follow-up surveys). To evaluate change in outcomes, published scales (when available) and scales developed for this program were administered in the preclass, postclass, and 6-month follow-up surveys. Open-ended questions were included to provide additional insight into class participants' responses to the program.

### ***Outcome Measures***

Four kinds of outcomes were used to assess changes for caregivers who took the classes:

#### *Self-care Behaviors*

Self-care behaviors were measured using standardized scales from other studies. The use of relaxation techniques and frequency of exercise were measured using single-item questions from Lorig et al. (1996). A Health Self-Care Neglect Scale (HSCN) to measure the caregiver's neglect of health-related self-care behaviors was adapted from prior research by the first author of this article and from Zarit's Health Behaviors Scale (S. Zarit, personal communication, August, 1999). The HSCN scale asks about 10 items related to self-care (with yes/no response mode). For example: "In relation to your *own* health, during the past month, have you... Put off going to the doctor, Failed to stay in bed when ill, or Eaten poorly" (internal reliability was determined from data collected from classes conducted in 2001: Cronbach's alpha = .7583.)

#### *Emotional Well-being*

Four measures were used to assess emotional well-being. The 3-item Positive Feelings about Caregiving Scale (PFCS) was developed for this program to measure how positively or negatively the caregiver felt about his/her role as a caregiver (e.g., "I am doing the best I can."). This scale is conceptually related to the concept of positive self-talk, which is taught as part of the Powerful Tools for Caregiving

curriculum (internal reliability from 2001 classes:  $\alpha = .7662$ ). Anger was measured using the 4-item anger/irritability scale from Pearlin and Mullen (1988), which reported internal consistency of .81. Guilt was measured using a 4-item scale adapted from the Feelings of Not Doing Enough subscale of the Caregiver Guilt Scale (Kingsman, 1992). This scale was introduced with the phrase "Indicate to what extent you have felt this way in the past month. . ." (e.g., "I felt that I have not done as much in the past as I could or should have for this person."). Internal reliability for the guilt scale determined from an earlier sample in the Powerful Tools for Caregiving program was  $\alpha = .7331$ . Depression was measured using the 10-item abbreviated Center for Epidemiological Study Depression scale (CESD10) (Andresen, Malmgren, Carter, & Patrick, 1994).

### *Self-efficacy*

Self-efficacy is a construct whose parameters are specifically defined by the behaviors or beliefs of interest (Lorig et al., 1996). For this program, a Caregiving Self-Efficacy Scale (CgSES) was developed with specific items related to the skills, behaviors, and attitudes taught during the Powerful Tools for Caregiving classes. The form used for the self-efficacy questions was similar to that used by Lorig et al. (1996), beginning with the statement, "How confident are you that you can. . .," with possible responses from "not confident at all" (1) to "totally confident" (10). The self-efficacy scale asked about key topics addressed in the curriculum: getting needed help, being able to relax, managing emotions, communicating with others, and making decisions about care. The self-efficacy scale underwent several phases of pilot-testing and refinement prior to 2002. For the analysis reported here, a summary measure for all 11 items included in the CgSES scale was computed (internal reliability  $\alpha = .9098$ ). A subscale for three items related to self-efficacy for communicating with family, friends, and the care receiver's doctor is also reported.

### *Knowledge and Use of Services*

Access to services was operationally defined as knowing if the services listed were available in the caregiver's community (service knowledge), and whether or not the caregiver had used the services in the past year (service use). The list of 13 services was defined from prior research and included: chore services, personal care, senior center, meals program, care facility (nursing home, foster, other), in-home respite, out-of-home respite (daycare), transportation, classes where you can learn about the medical condition of the person you are helping, support group, case management, legal/financial planning, and counseling. Summary variables for service knowledge and for service

use were determined by summing the services that the class participant marked as knowing about, or the services he/she had used in the past year.

## RESULTS

Demographic characteristics of the participants who completed the class series are reported in Table 2. The majority of class participants were female, retired or otherwise not employed, and highly educated. Non-Caucasians, were 18% with 8% Latino and 6% Asian/Pacific Islander. About half of the class participants (55%) were caring for someone with Alzheimer's disease or other dementia, although 81% reported that the person they were caring for had some degree of memory loss. We also compared demographic and caregiving data for class participants who completed the classes with those who did not complete the classes. (As noted above, completers were defined as class participants who attended four or more classes). Class participants who provided more household help for their family members were significantly less likely to complete the class series (comparison of mean amount of care ( $t$  test = 2.17;  $p$  = .034)). There were no significant differences between completers and noncompleters based on class participant's age, sex, minority status, education level, relationship (spouse versus nonspouse caregiver), low-income versus nonlow-income, caregiving for someone with dementia versus caregiving for someone without dementia, and whether or not the care receiver was institutionalized.

Table 3 reports the class participants' ratings for the classes for class completers using a 10-point rating scale from 1 (poor) to 10 (excellent). The average ratings for the six classes in the series ranged between 8.85 for the first class in the series and 9.26 for the last class in the series. The mean overall rating for the entire series for the sample was 9.25. For the 33 separate classes, the mean overall ratings for the class series ranged from 7.60 to 10.00.

Class participants were also asked in the postclass evaluation and the 6-month follow-up if they were using the tools taught during the class. At the end of the class series (postclass survey), 82% reported using action plans, 78% reported using I-messages, 77% reported using relaxation tools, 67% reported using positive self-talk techniques, and 35% reported using long-range goal setting techniques. At the 6-month follow-up, 50% reported using action plans, 46% reported using I-messages, 72% reported using relaxation tools, 66% reported using positive self-talk, and 24% reported using long-range goal setting techniques.

**Table 2. Profile of class participants who attended four or more classes (N = 226)**

Demographic characteristic	Class data
	61(mean) Range: 26–89
Age of class participants	
Caregivers' relationship to care receiver	
Spouse	36%
Adult child	51%
Caregiver is sibling or other relative of care receiver	13%
Caregiver gender	
Female	78%
Male	22%
Caregiver ethnicity	
White	82%
Latino	8%
Asian/Pacific Islander	6%
Native American	3%
African American	1%
Employment status of caregivers	
Employed full- or part-time	33%
Retired or otherwise not employed	67%
Low-income	18%
Level of education	
Post-high school education	68%
High school graduate or less education	32%
Care receivers' living arrangements	
Lives with caregiver	55%
Lives alone	24%
Lives in nursing home, adult foster care, or assisted living	13%
Other arrangement	8%
Amount of care provided	
Provides daily or almost daily personal care	25%
Provides daily or almost daily household help	16%
Provides daily or almost daily help arranging for services or care, taking person to the doctor, etc.	26%
Illness conditions of care receivers <sup>1</sup>	
Alzheimer's/dementia	55%
Heart disease	20%
Stroke	20%
Diabetes	20%
Parkinson's disease	12%
Cancer	8%
Extent of memory loss <sup>2</sup>	
No memory loss	19%
Mild memory loss	31%
Moderate memory loss	34%
Severe memory loss	17%

<sup>1</sup>Care receiver may have more than one illness condition.<sup>2</sup>Total not equal to 100% due to rounding.

**Table 3. Weekly and overall participant ratings of program, 1–10 point class rating scale<sup>1</sup> (N = 204)**

	N	Mean (SD)
Week 1	179	8.85 (1.3)
Week 2	191	8.96 (1.2)
Week 3	185	9.14 (1.0)
Week 4	169	9.03 (1.1)
Week 5	177	9.09 (1.0)
Week 6	132	9.26 (0.9)
Overall rating	204	9.25 (1.0)

<sup>1</sup>1 = poor, 10 = excellent on class rating scale.

Turning to the outcomes analysis, Table 4 reports the comparisons of means for the preclass and postclass surveys. Significant positive change (in the desired direction) was reported in all areas of expected outcomes: emotional well-being, self-care behaviors, self-efficacy, and use and knowledge of community services. As shown in Table 5, significant positive outcomes were sustained at the 6-month follow-up for most of the outcomes. The exception was nonsignificant change between the preclass survey and 6-month follow-up in exercise frequency.

Because of the low response rate for the 6-month follow-up, we compared the characteristics of class participants who (a) returned preclass and postclass evaluations but not 6-month follow-up evaluations, and

**Table 4. Class participant outcomes: Comparison of pre-class and post-class data (paired t tests)**

Outcome	Preclass			Postclass		t test
	N	Mean	(SD)	Mean	(SD)	
Positive feelings about caregiving	164	5.37	(2.4)	5.76	(1.9)	-2.32*
Anger	172	3.64	(2.2)	2.55	(1.7)	6.96***
Guilt	163	3.11	(2.5)	2.22	(1.8)	5.08***
Depression (CESD10)	114	3.51	(2.5)	2.17	(2.2)	6.36***
Self-efficacy (summary)	148	55.90	(16.4)	73.34	(16.2)	-11.71***
Self-efficacy for communication	159	20.12	(7.0)	25.40	(8.4)	-6.79***
Health self-care neglect	178	3.40	(2.3)	2.40	(1.9)	6.05***
Exercise frequency	182	2.05	(1.5)	2.47	(1.3)	-4.41***
Frequency of relaxation	173	1.29	(1.4)	2.02	(1.1)	-6.60***
Service use	184	2.54	(2.5)	3.39	(2.8)	-5.33***

\*p < .05.

\*\*p < .01.

\*\*\*p < .001.

**Table 5. Class participant outcomes: Comparison of preclass and 6-month follow-up (paired *t* tests)**

Outcome	Preclass			Follow-up		<i>t</i> test
	<i>N</i>	Mean	( <i>SD</i> )	Mean	( <i>SD</i> )	
Positive feelings about caregiving	58	5.13	(2.2)	6.14	(2.1)	-3.42**
Anger	59	3.51	(2.2)	2.41	(2.0)	3.66**
Guilt	53	3.23	(2.5)	2.52	(2.1)	2.44*
Depression (CESD10)	47	3.62	(2.2)	2.68	(2.1)	3.17**
Self-efficacy (summary)	51	53.76	(13.1)	66.69	(13.2)	-7.46***
Self-efficacy for communication	54	19.83	(5.7)	23.50	(4.9)	-4.85***
Health self-care neglect	69	3.43	(2.2)	2.48	(2.0)	3.26**
Exercise frequency	63	2.22	(1.4)	2.43	(1.4)	-1.11 ns
Frequency of relaxation	60	1.15	(1.3)	1.77	(1.4)	-3.14**
Service use	69	2.87	(2.5)	3.62	(3.0)	-2.37*

\**p* < .05.\*\**p* < .01.\*\*\**p* < .001.

(b) those who reported preclass and 6-month evaluations. There were no significant differences at the *p* < .05 level of significance between these two groups in the demographic characteristics or caregiving characteristics reported in Table 2, in overall class rating, or in the preclass scores on the outcome measures. However, several important characteristics that may affect outcomes were marginally significant. Of the participants who returned 6-month forms, 43% were spouse caregivers (versus nonspouse caregivers). Of the class participants who returned postclass forms but not 6-month forms, 30% were spouse caregivers (*p* = .057). Also, 75% of the participants who returned 6-month forms were retired or otherwise not employed, whereas 62% of the participants who returned postclass forms but not 6-month forms were retired or otherwise not employed (*p* = .067).

## DISCUSSION

### *Practice Implications*

The evaluation of classes offered in Oregon during 2002 provides evidence of the benefits of the Powerful Tools for Caregiving program. Not only did family caregivers report high satisfaction with the program, significant positive outcomes were found in improved self-care behaviors, emotional well-being, caregiving self-efficacy, and knowledge and use of community services. Most, though not

all, of these outcomes were maintained 6-months after completion of the class series. The high reported use of the tools taught during the program suggests that the curriculum offers helpful ways for class participants to use what they learn in their roles as caregivers. The success of the program may be attributed to several key aspects of the program. The carefully designed and scripted curriculum and class-leader training program ensure uniformity in presentation and effective management of the class setting. The generally high overall ratings suggest that the curriculum works well for coleaders with a wide range of prior experience in training and education, and that it can be effectively used in a wide variety of settings.

### ***Limitations and Need for Further Research***

Some important limitations to the evaluation should be mentioned. First, not all persons who registered for the class completed the program. The dropout rate was 28%, which was higher than the average reported for psychoeducational programs (16.1%) in a recent metaanalysis of caregiver interventions (Sörensen, Pinquart, & Duberstein, 2002). The finding that class participants with greater responsibilities for helping their relative with household tasks were less likely to complete the class suggests that, for some caregivers, the 6-week class schedule may be too long. A reduced number of sessions might be preferred. In the future it would be beneficial to assess other factors that contribute to the rate of noncompletion. Some possible factors include: poor health of the caregiver, and quality of class leadership. Also possible is a misunderstanding about the focus of the classes on caregiver self-care, rather than on training caregivers to provide care for the care recipient.

Additional limitations are the low response rate for the 6-month follow-up, and the lack of randomized treatment/control design. These limitations suggest a need for further research to evaluate the benefits and outcomes of this program. The lack of significant differences at the  $p < .05$  level suggest that missing data were missing at random. Differences in outcomes immediately after the completion of the class series and at the six-month follow-up are not likely to be due to differential lack of response between these groups of respondents. The near significant difference between the respondent groups in relationship (spouse versus nonspouse) and employment status may suggest differences that affected the differential outcomes for participants who did or did not return the 6-month evaluation forms. This highlights the need for further evaluation of the Powerful Tools for Caregiving program in a controlled trial.

However, the high satisfaction ratings for the classes and the positive outcomes reported by class participants who completed the classes suggest that the Powerful Tools for Caregiving program has great promise in improving the well-being of family caregivers and reducing the negative impacts of caregiving. As one class participant reported, “[The class] opened my eyes to the stresses of caregiving and the long-term effects that stress has on the body and mind. It also helped me to see the warning signs of my own stress/depression.”

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