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Case Study

“Powerful Tools for Caregivers”: Teaching Skills That Reduce Stress and Increase Self-Confidence

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Educational Objectives

1. Describe caregiving stress and burnout symptoms and effects experienced by older caregivers.
2. Report implementation and evaluation of the “Powerful Tools for Caregivers” workshop, which is designed to increase knowledge and skills in caring for elders and reduce caregiver stress.
3. Suggest ways to alleviate caregiver burden at both micro and macro levels.

Background

Caring for an older adult can be a full time job that sometimes results in increased stress and caregiver burden. With the growth of the older population, especially those

ages 85 and above, and the incidence and prevalence of chronic disease and illness in old age, informal caregivers are becoming a more valuable, even essential, resource. Changes in health care policies, rules, and reimbursement procedures have shifted more of the care responsibility for elders from the formal to the informal (family and friends) system. Family caregiving is valued at \$257 billion annually, more than twice the spending on institutional and home care combined. About four in five (78%) adults receiving long-term care at home rely entirely on family and friends; only 8% rely entirely on formal services. Care recipients ages 50 and above are found in more than 22.4 million American homes (Feinberg & Newman, 2004; Sawatzky & Fowler Kerry, 2003).

Many caregivers experience negative emotional and physical symptoms due to the demands of their role. For example, Sit et al. (2004) found that 40% of the 102 caregivers they surveyed reported somatic symptoms, including reduced physical strength, headache, poor appetite, pain, and stomach discomfort. While each illness/

disease poses unique challenges, dementia in particular creates a more intense caregiving relationship, and can easily exacerbate caregiver stress to the point of emotional strain and depression. Caregiver burnout, which occurs when a caregiver reaches a state of physical, emotional, and mental exhaustion, increases in caregivers who are older and in poor health themselves. In addition, Feinberg & Newman (2004) recently estimated that caregivers lose an average of \$659,000 in total wealth due to their providing care.

The rise in informal eldercare provided by older persons and the correlation between caregiver age and strain/burnout begs supportive solutions on both micro (family) and macro (policy) levels. Research supports the need for educational programs to deliver targeted, applied eldercare knowledge and skills to caregivers to reduce their physical and emotional strain. Interventions that focus on caregiver needs benefit both the caregiver and the care recipient. Caregiver workshops that provide education and information on

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available resources and services and that promote self care reduce the likelihood of caregiver burden and depression (Hepburn et al, 2001).

“Powerful Tools for Caregivers”

“Powerful Tools for Caregivers” (PT4C) was developed as an educational program targeted for any family member who is a caregiver to a parent, spouse or older adult. The program provides information and behavioral tools to improve caregiving ability, promote self-care, and increase self-confidence.

The conceptual foundation of PT4C is the *Chronic Disease Self-Management Program* developed by Dr. Kate Lorig and her colleagues at Stanford University’s Patient Education Research Center. The PT4C program/protocol was originally written by Vicki Schmall, Marilyn Cleland, and Marilyn Sturdevant, supported by a grant from Meyer Memorial Trust to Legacy Health System. Mather LifeWays, helped by an Administration on Aging grant, further refined PT4C, and AARP subsequently adopted the program.

PT4C was originally designed to be delivered via six weekly 2.5-hour sessions. Though designed for informal family eldercare providers, much program content is applicable to other groups, such as paid caregivers. The sessions have an educational focus, each being comprised of a set of topics to be covered and skills to be taught. The content delivery context is highly interactive, with participants encouraged to share experiences

and information and to be mutually supportive. PT4C is typically facilitated by two co-leaders who have completed a two-day training. Leaders receive a copy of *The Caregiver Helpbook* (Schmall, Cleland & Sturdevant, 2000) and a Class Leader’s Guide. The guide provides an agenda, script, and handouts for each session, ensuring consistency across all PT4C workshops. Each modular session has specific learning objectives that provide knowledge and skills needed to enhance caregiver self-efficacy, such as developing action plans, providing feedback, seeking solutions, stress-reduction techniques, improving communication skills, and dealing with difficult emotions like anger, guilt, and depression.

Class one focuses on self-care. Following introductions, participants are asked to identify specific challenges of caregiving. They view *The Dollmaker*, a video emphasizing the consequences of self-neglect. Participants are also informed of available community resources and learn to set goals as a self-care tool. The second class identifies caregiving stressors and introduces tools to reduce caregiving stress. Class three focuses on effectively communicating feelings, needs, and concerns. The fourth class extends class three to communicating in challenging situations, such as with dementia care recipients and healthcare professionals. The theme of class five is the necessity of learning from and constructively dealing with emotions. The final class provides tools to assist with making difficult caregiving decisions. (Subsequent to this, PT4C has been

offered as a four-session workshop, and a 90-minute version is being pilot-tested and evaluated.)

Typically the PT4C workshop is free and respite services are often provided. Participants receive a copy of *The Caregiver Helpbook* (normally \$25; available in many public libraries); many sponsoring agencies utilize Family Caregiver Support Program funds, obtain external sponsorship, or charge a small fee to cover the cost of the book.

Case Study #1

For the past four years Lynn, a 70 year-old retired school teacher, has been the primary caregiver for her husband, Albert, who has Alzheimer’s disease. He is rapidly becoming more impaired; he is very forgetful and can no longer be left alone. Albert requires assistance with eating, dressing, bathing, toileting, and all Instrumental Activities of Daily Living. At least for now, he can transfer and ambulate independently. Lynn arranged for a friend to stay with her husband so she could attend the four PT4C sessions.

Lynn was neatly dressed and appeared content in her caregiver role. At first Lynn remained quiet and did not participate in group discussions. When asked to describe her sources of stress, Lynn began to describe her husband’s extreme demands. Lynn stated that she becomes very frustrated when caring for her husband. She had no previous experience with Alzheimer’s disease and felt unprepared to provide the care her husband needs. Lynn expressed

resentment toward Albert because he requires all her attention. Lynn enjoys shopping and eating out, but she can no longer take Albert, due to his unpredictable behavior. She recalls becoming very embarrassed when he began yelling in the restaurant. Lynn felt socially isolated and no longer invited friends over to her house.

As the PT4C workshop progressed, Lynn became more open and began to forge friendships with other participants. She learned how to reduce stress, ask for help from others, and deal with difficult emotions. She developed skills to deal specifically with dementia caregiving and became more confident in her caregiver role. Following the workshop, Lynn reported feeling less stress than she had felt prior to the workshop. Five months later, the PT4C facilitator encountered Lynn, who was out shopping. Lynn said she has been making time for herself and had asked for help from her extended family. PT4C gave Lynn knowledge and skills that improved her self-confidence and promoted a healthier caregiver relationship. She related that she found the workshop very helpful and had already referred a friend.

Case Study #2

Tammy, 67 years old, provides care for her father and her disabled husband. Tammy has been her father's caregiver since 1979, the year her mother died. Her father, who has significant memory loss, requires constant supervision due to his forgetfulness and confusion but can perform most Activities of Daily Living independently.

Tammy has been caring for her husband for two years, following a car accident that cost him the use of his legs. Her husband uses a wheelchair, but has fallen several times in the past six months when transferring. Between the demands of her father and her husband, Tammy stated that she feels stretched near the breaking point.

Tammy decided to participate in PT4C mainly as a social outlet. She said she had very little time for herself and often neglected her own needs. She had begun to experience headaches, which she attributed to caregiver stress. At the end of each class, participants make an action plan for the coming week, and Tammy decided that she would walk three times. She admitted she has gained weight and believed it to be the cause of her knee pain; she thought that walking would be both emotionally and physically beneficial. At the conclusion of the PT4C series, Tammy said that she felt less stressed and had fewer headaches than prior to the workshop. She reported that she had found support in the class and maintains phone contact with other participants. She continues to walk regularly. Tammy gave PT4C excellent ratings, noting the relaxed atmosphere in which to share feelings and experiences and the value of meeting other caregivers in similar situations.

Evaluation

The premise of PT4C is that by teaching caregivers how to care better for themselves, benefits accrue to both caregivers and care recipients. In the years since the initial development of PT4C, research, evaluation, and revision

have helped ensure its continued success. However, when North Carolina's Region D Area Agency on Aging, collaborating with Appalachian State University's (ASU) Gerontology Program, prepared to offer PT4C in summer 2006, shortcomings were identified in the evaluation protocol provided with the PT4C materials. The evaluation did pose questions about "how helpful" various PT4C elements were, "how the program has benefited you personally," and what a participant would "tell someone who is interested in taking the course." While such information is useful, there were neither baseline nor post-PT4C measures of caregiver stress or caregiving knowledge and skills. Also, despite specific and measurable learning objectives for each PT4C session, the PT4C evaluation did not ask participants to demonstrate acquired knowledge. It was conceivable that participants could "feel good" about PT4C while not actually learning anything. This would, indeed, be an undesirable result.

Consequently, ASU's Gerontology Program developed two evaluative instruments: a *Caregiver Self-Assessment Survey* (measuring caregiver stress), based on materials from the North Carolina Family Caregiver Support Program and the American Medical Association, and a *Learning Objectives Survey* that measured knowledge of specific information/skills delivered by PT4C. (Examples of the latter include: "Name two activities that help reduce stress" and "Define guided imagery.") Both instruments were administered to the participants in two Region D PT4C

programs at the start of the first session, at the end of the last session, and one month after the last session.

The results were presented at the 2006 NC Conference on Aging and were gratifyingly positive (Rosenberg, Gouge & Craig, 2006). From the pre-test to the post-test to the one-month follow-up, there were statistically significant reductions in self-reported caregiver stress and gains in caregiving knowledge. (It may be that the knowledge increase between the post-test and the one-month follow-up is attributable to participants continuing to refer to *The Caregiver Helpbook*, having their application of new knowledge reinforce retention of that knowledge, and the informal support group meetings that continued after PT4C.)

Conclusion

The amount and complexity of care being provided by informal caregivers to older family members are increasing and will continue to do so. These caregivers, however, often lack relevant knowledge, skills, and supports, and are, thereby, vulnerable to increased caregiver burden and stress. The consequence can be inefficient caregiving, negative emotions and relationships, and maladaptive behaviors. Thus, it is important, at both micro and macro levels, to improve caregiver functioning, self-confidence, and self-care, and to reduce stress in informal caregiving relationships. The "Powerful Tools for Caregivers" workshop demonstrably builds knowledge and skills and reduces stress for informal

eldercare providers. At the same time, there are a number of policy recommendations that could help further to alleviate family/informal caregiver burden; Feinberg & Newman (2004) suggest increasing funding for the National Family Caregiver Support Program, providing tax credits and other economic incentives, raising employers' awareness of and support for employees with elder-care responsibilities, and multiplying available resources for technical assistance and training of family caregivers.

Study Questions

1. List some possible negative consequences of informal eldercare for the caregiver and care recipient.
2. What is "Powerful Tools for Caregivers (PT4C)"? How does it work? How well does it work?
3. What recommendations could be made, at both micro and macro levels, to relieve informal eldercare burden and reduce negative consequences?

About the Authors



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Caregiver Stress Test

There are a number of instruments to measure caregiver stress. This one (CFS Caregivers, 2007) is representative and is intended to help the caregiver become aware of her/his emotions and strains.

Which of the following are seldom true, sometimes true, often true, or usually true?

- * I find I can't get enough rest.
- * I don't have enough time for myself.
- * I don't have time to be with other family members beside the person care for.
- * I feel guilty about my situation.
- * I don't get out much anymore.
- * I have conflict with the person I care for.
- * I have conflicts with other family members.
- * I cry every day.
- * I worry about having enough money to make ends meet.
- * I don't feel I have enough knowledge or experience to give care as well as I'd like.
- * My own health is not good.

If the response to one or more of these areas is usually true or often true, it may be time to begin looking for help with caring for the care receiver and help in taking care of yourself.

PT4C is currently available in 20 states, but not yet Virginia. For more information, contact Suzanne (Cameron) Black at the North Carolina AARP at (919) 508-0269 or e-mail slcameron@aarp.org.

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Editorials

From the Director, Virginia Center on Aging

Edward F. Ansello, Ph.D.

Re-imagining the experience and study of aging

I recently returned from Okinawa and an awesome experience, not in the "shock and awe" sense of late military campaigns but rather in the jaw-dropping, humbling sense when one encounters something truly profound. With seven other Americans, I joined an assemblage that totaled some 80 people from several Southeast Asian nations, drawn to this longest-lived prefecture of the world's longest lived country to re-invent gerontology.

Led by Dr. Ryo Takahasi, a small group of Japanese and American colleagues have been working together the past three years toward developing a curriculum that would help people to understand the experience of aging. With a little reflection, one can appreciate the enormity of the task. While Japan can boast an advanced commitment in geriatric medicine, with almost five times as many of their schools of medicine having full departments of geriatrics as ours, there are almost no gerontology programs in their institutions of higher education. We have recognized that, in working to establish programs, here is the opportunity to re-imagine or re-conceptualize what would constitute "gerontology" and how it is taught. Not that we are doing a bad job here in the United States and in other Western

countries. Where it already exists, the traditional core curriculum in gerontology includes social, psychological, and biomedical aspects of aging, with public policy sometimes included. We American gerontologists have even labeled these the "standards."

What we have been asking leading up to the Okinawa conference is, *What if gerontology could be the door through which we come to understand not only human aging but human life? What would we add or subtract in the curriculum? How would we shift our stance or point of reference in facing our subject matter?*

Clearly, this has become a "work in progress." After many hours of meetings and months of communication, our group suggested adding three subject areas to the core curriculum, calling them "vectors" to suggest interactive, reciprocal paths between them and people: business, information technology/communication, and education. Each may profoundly alter the experience of aging and, vice versa, the aging of the population may precipitate profound changes in their operation; so, for instance, technology might enable watchful caregiving at a distance through in-home sensors like those currently in teapots in Japan which signal family members when the pot is not lifted for the elder's daily cup of tea, and education might be the vehicle for lifelong learning or quests after the purpose of life for some older adults; reciprocally, larger numbers of questing adults or tech-savvy Baby Boomers growing old may transform education and technology, etc.