

## **APPLICATION FORM**

**Title of Entry:** Empowering Caregiver Transition: Impact of Caregiver Training and Support Group Services

**Division:** Small Organizations

**Award:** Community Champions

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## **Empowering Caregiver Transition: Impact of Caregiver Training and Support Group Services**

**Description of the Opportunity/Problem:** Long-term care management of chronic health conditions and availability of support network services to those caring for persons with chronic conditions such as stroke and traumatic brain damage have not advanced as quickly as acute medical management of these conditions (Griffin et al., 2012). Typically responsibilities involving patient aftercare transfer to a family member, parent, or spouse upon discharge from a hospital or institutional setting. With shorter hospital stays and rehabilitation services becoming more complex to access, unpaid caregivers are left with providing more intense care for a longer period of time (Ekstam, Johansson, Guidetti, Erikson, & Ytterberg, 2015). In a study completed by Ekstam, et al. comparing perceptions of caregivers with that of their loved one who had a stroke, caregivers reported less satisfaction in the length of rehabilitation services and amount of time they were provided with training and follow-up. Persons with stroke in this study received inpatient and outpatient rehabilitation services for an average period of three months (Ekstam et al., 2015). During this time, caregivers were left with continued unmet needs and reported as their loved one's status changed they felt isolated and on their own (Ekstam, et al., 2015; Persson et al., 2015). The target audience of this evidence-based program were caregivers of adults with stroke, brain injury, Parkinson's disease, and multiple sclerosis. The goal of the program was to demonstrate how caregiver education programs can increase the health and well-being of caregivers.

**Evidence:** As care complexities rise and families are considering ways of managing the care of their loved ones at home, caregivers identify that combined strategies are required to help them manage their burden and concerns to avoid injury to themselves or the care recipient (Thinnes & Padilla, 2011). Interventions during rehabilitation services were helpful to caregivers which combined both clear instruction for direct care and enhancement of stress-reduction techniques to cope with the longevity of caregiving (Thinnes & Padilla, 2011). Furthermore, interventions providing caregivers with education on stress reduction and meditation have been shown to be effective in improving perceived level of stress and longevity in the caregiving role (Amen et al., 2010).

**Baseline Data:** The quantitative measure Short Form 12v2 Health Survey was used pretest to assess caregiver perceived health and wellness. No formal standing support group providing specific *caregiver* education existed before this program. The participant median Mental Health Component (MCS) Subscore at the beginning of the program was 38.88 and the Physical Health Component (PCS) Subscore was 45.81. Non-gender or age related normative data based on the United States adult population is 50.00 ( $\pm$  10 points) for both subscores (see Appendix A: Individual Caregiver Results on the SF 12v2 Health Survey, p. 8).

**Intervention:** The caregiver curriculum Powerful Tools for Caregivers<sup>©</sup> was provided over six sessions in an educational support group format for caregivers of individuals with neurological conditions. The sessions aimed at increasing caregiver self-care, stress management, and reducing caregiver perceived burden while improving their knowledge of resources for caring for their care receiver (Powerful Tools for Caregivers, 2016).

**Results:** All caregivers in the program reported improvement in their overall health and wellness as evidenced by improvement of scores on a standardized outcome measure known as the Short Form 12v2 Health Survey. MCS was 47.35 and PCS was 50.73 at the conclusion of the program (See Appendix A: Individual Caregiver Results on the SF 12v2 Health Survey, p. 8).

**Assessment:** Multiple challenges exist in providing at-home care for an individual with new onset or chronic illness within the United States (National Alliance for Caregiving, 2015). Spouses, partners, adult children, and extended family members now serve in the unpaid work force known as *informal* caretakers (Sakakibara, Kabayama, & Ito, 2015). Informal caretakers are typically defined as those persons who care for family members in their or their family member's home without pay (Keglovits, Sommerville, & Stark, 2015). Family caretakers assume responsibility for not only the physical care associated with taking care of others, but the emotional and financial burden of care for family members as well. In fact, the National Alliance for Caregiving (NAC) estimates that more than 65 million Americans care for a family member or loved one (2015). Eighty-six percent of all care providers are first degree relatives while 36% of all caregivers provide care to a parent (NAC, 2015).

An extensive search of the literature was conducted from January 2016 through March 2016 consisting of various key words and databases. The appraised articles were selected from the following journals and sources: *The American Journal of Occupational Therapy*, *Archives of Physical Medicine and Rehabilitation*, *Rehabilitation Psychology*, *Journal of Rehabilitation Medicine*, *International Journal of Rehabilitation Research*, *Stroke*, *Journal of Head Trauma Rehabilitation*, *International Journal of MS Care*, *British Medical Journal*, and *The Gerontologist*. Various studies and sources were obtained to review in order to build a portfolio of evidence for the caregiver's risk of physical and mental health problems, issues facing informal caregivers, and the interventions available and conducive to promoting balanced caregiver-care recipient relationships. A total of 45 articles were located and 16 were selected to form the Critical Appraisal Portfolio to support this evidence-based pilot study. The selected articles were published from 2005 to 2015 and were selected on relevance to the topic, quality, rigor, and applicability to the pilot study. The critically appraised portfolio contained five Level I studies, one Level II study, eight Level III studies, and two Level VI studies.

The organization also conducted focus groups to determine the needs of caregivers in our local community to determine interest for a caregiver education class. Feedback was positive from these focus groups. In conjunction, the hospital leadership supported the initiative due to increasing emphasis on caregiver programming and passing of the CARE Act within the state of Pennsylvania which became law in 2017. Staff members within the institution were also queried for their interest in helping to recruit and establish a team of individuals willing to assist with the pilot program. The formal curriculum *Powerful Tools for Caregivers*® was selected as the intervention and evidence-based curriculum for the pilot program. Two staff members became certified instructors. Inclusion criteria/exclusion criteria were created and IRB approval was obtained through Chatham University in the fall of 2015. The pilot study was initiated on January 11, 2016 and the intervention was provided for six, consecutive weeks. See Table 1.1 below which includes the pilot group participants.

Table 1.1

*Caregiver Participants and Demographics*

Caregivers n=9	Gender	Age	Relationship to Care Recipient	Care Recipient Condition
C-1	Male	66	Husband	Multiple Sclerosis
C-2	Male	61	Husband	Brain Injury
C-3	Female	59	Sister	Stroke
C-4	Male	29	Son	Stroke/Brain Injury
C-5*	Female	64	Sister	Stroke/Brain Injury
C-6	Male	67	Ex-Husband	Stroke/Brain Injury
C-7	Female	68	Wife	Multiple Sclerosis
C-8	Male	87	Husband	Stroke
C-9	Female	58	Daughter	Stroke

\*Completed only 4 of the 6 classes.

**Intervention:** Participants for this pilot study included volunteer caregivers caring for persons with chronic neurological illness such as stroke, brain injury, Parkinson's disease, and multiple sclerosis. This evidence-based caregiver program intervention entitled Powerful Tools for Caregivers© was implemented over a six-week program from January 1, 2017 to February 28, 2017. The format for the sessions included six distinct structured lessons for 90-minutes each session.

**Week one.** Session one set the tone for the six-week curriculum and for the caregiver participants to get to know one other by allowing sharing of their caregiving situations and problems experienced in the role of a caregiver. The introductory material of the Powerful Tools for Caregivers© series emphasized the importance of the caregiver in the dyad relationship. "Tools" and strategies for caregiver self-care were explored in order that each participant had time to consider their own needs. While the session did not focus on the conditions of the care recipients, additional resources for stroke, brain injury, Parkinson's disease, and multiple sclerosis were available for each caregiver who chose to receive the information from the disease-specific lending library. A caregiving 20-minute video was viewed and a short reflective discussion occurred afterward regarding the physical, emotional, social, and financial challenges of caregiving. At the end of the session, the purpose of the personal action plan was explained by the duo of group facilitators and the participants were able to write down their personal goal for the upcoming week. Each caregiver was encouraged to share their goal and their confidence level in trying to meet the personal action plan before the next class.

**Week two.** Caregiver participants were encouraged to take turns and share their experiences in carrying out their Action Plans. The overall class focus centered on the importance of managing life stressors. Identification of early warning signs of stress, identifying sources of personal stress, changing controllable factors, and taking healthy actions to avoid the consequences of stress was discussed. The group leaders addressed forms of negative self-talk and the ways caregivers can improve their overall wellness by changing self-talk to more positive recognition of their role as a caregiver. The class concluded with a new "tool" in the caregiver toolbox – deep breathing relaxation exercises.

**Week three.** The third session opened with each participants report on how they did with their personal action plan for the week and use of the deep breathing relaxation tools. The discussion and group exercises for the week focused on tools for communication between the caregiver, care recipient, and other care providers. Through brief dramatizations, the participants were able to see and practice the power of "I" and "you" messages. The topic of the session focused on controlling how we can interact with others who may have challenging behaviors, inability to communicate because of deficits such as aphasia, or other limiting deficits. Additional tools and resources for dealing with communication and cognitive factors during caregiver-care recipient interactions were provided and new goals were drafted.

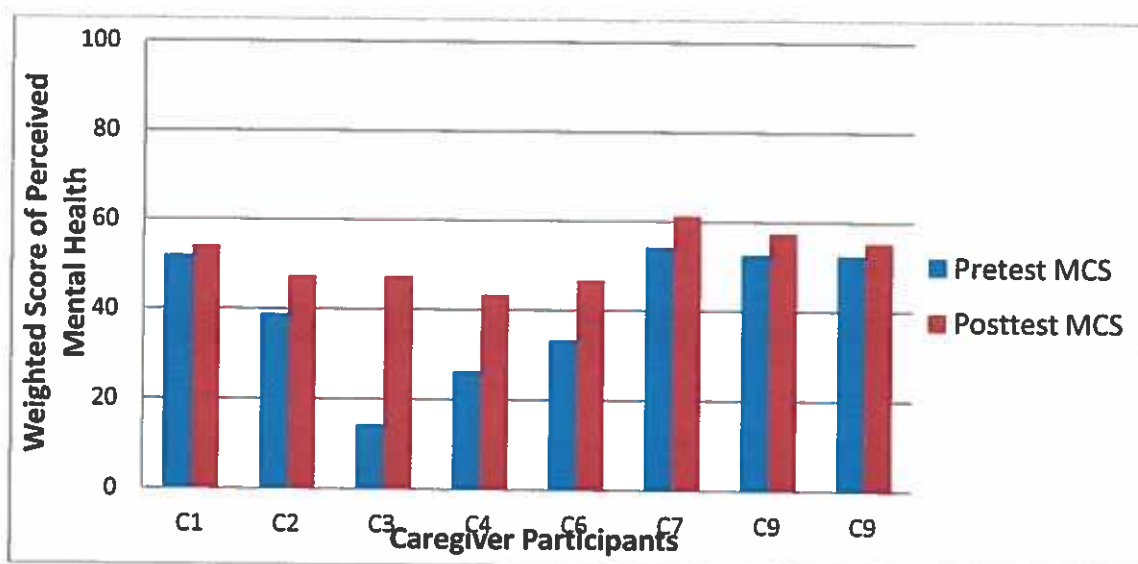
**Week four.** The weekly outline included handouts of "tools" related to assertive or Aikido style of communication using "I" statements. Caregiver participants learned the style of communication incorporating the DESC process – describe, express, specify, and list consequences form of communication. A segment of the curriculum was dedicated to communicating with persons with memory loss or impairments as related to neurological illness or injury.

**Week five.** Each caregiver was encouraged to list emotions related to their past and present participation in caregiving. Feelings of anger, guilt, and depression were reflected on throughout the group. Resources for additional professional help were made available for interested caregiver participants. Again, each caregiver participated in making a personal action plan and participated in sharing their goal with the group for the upcoming week.

**Week six.** The final class focused on mastering caregiving decision-making. Resources were provided for helping caregivers find assistance for respite care, agencies, or healthcare equipment vendors in their immediate area for current and future needs. A brief discussion on planning for the future and sharing important caregiving decisions as a family was incorporated. Each participant was provided with an opportunity to make a long-range personal action plan for the next 3 months. The caregiver participants had an additional opportunity to select resources from the disease-specific lending library at the hospital.

**Results:** Each caregiver reported their perceived level of health and wellness by circling the description which best fit their perception of their ability at week one and week six using the SF 12v2 one-week recall version of the measure. The SF 12v2 overall score for each caregiver was derived for each of the caregivers via the pretest data collection on all 12 domain items. In addition, each of the 12 domain items captures eight concepts of overall health and wellness: physical functioning, role limitations due to physical health, bodily pain, general health, vitality (energy/fatigue), social functioning, role limitations due to emotional problems, and mental health (psychological distress and psychological well-being). The pre-test and the posttest outcomes for both the Physical Component Score (PCS) and the Mental Component Score (MCS) were derived for each caregiver (see Appendix A: Individual Caregiver Results on the SF 12v2 Health Survey , p. 8). Each of these component scores is normality based using scales established across the United States where the established mean score is 50 with a standard deviation of 10 in the general U. S. population (Ware, Kosinski, Keller, 1995).

While the physical functioning components of perceived health varied with each individual, the perceived mental health increased across all caregiver categories independent of gender, age, or care recipient diagnostic characteristics improved over the course of the six weeks. Each of the caregivers reported an improvement in the sub-scores representative to energy level, participation in social activities, emotional functioning, and overall perception of mental health. Questions included the caregiver's response to how much they perceived they accomplished during the week as a result of feeling depressed or anxious, if they perceived their daily activity participation was performed less carefully as a result of feelings of depression or anxiety, if they felt improvement in their feelings of calmness or peacefulness, and whether their level of energy improved. Each of the caregivers reported a higher level of functioning from pretest to posttest on these items. See Table 2.1 below.



As a result of the pilot study, the program is going to continue and include caregivers of any individual with any chronic condition or illness due to the successful results of this pilot program and the interest/waiting list generated from the first round of the program. Follow-up consultative feedback was gathered from the original group of caregiver participants in the pilot who indicated their satisfaction via qualitative reports that the program had made a significant impact on their daily routine. The group also had the opportunity to rate their experience with the program on a Likert scale which yielded an overall likelihood to recommend the program at 9.4/10 possible points. A sustainability plan has been drafted to include this program in the overall program structure within the hospital's existing support group network. The program has been rescheduled to occur once per quarter to allow for ongoing availability of this necessary program to caregivers in need of support and personal wellness.

**Adaptability:** Caregiver health, wellness, and readiness are essential to our current healthcare continuum. It is estimated that when the Baby Boomer Generation turns 85 in 2031, the United States population requiring some caregiver assist will grow from 6 million to 21 million (NAC, 2015). Health care facilities need to promote programs that address caregiver needs to provide sustainable care. In 2013, it was estimated that 48 billion dollars were spent by Medicare and Medicaid on paid caregiver services (AARP, 2015). During this same period, it is estimated that if family caregivers were recognized and received payment for the care they provided it would nearly double this figure to over 90 billion dollars (AARP, 2015). Caregiver education programs are one means to ensure this “resource” is available to keep up with the demand.

This caregiver education program is adaptable and is able to be reproduced throughout healthcare organizations or in community centers. The Powerful Tools for Caregivers© program is nationally available and is accessible to healthcare providers with a wide variety of disciplines including nursing, social services, allied health, and mental health backgrounds. The overhead to incorporate a program is relatively low requiring two trained instructors and a nominal fee for workbooks and handouts. Training requires two days of classroom and interactive instruction. The program can be incorporated into inpatient, outpatient, homecare, or community settings and is applicable to caregivers caring for children through late adulthood. The educational program is suitable for those working with populations ranging from autism, dementia/Alzheimers, chronic disease, management, or end of life issues.

Caregivers need support throughout their lifespan and not just periodic point-of-service contact when their care receiver is discharged from an institution or hospital. The type of caregiver education provided in this pilot program was easily integrated into the organization since it was consistent to the organization’s mission of promoting access to wellness services for it’s clients. The program was also free of charge for the participants and was held at times most convenient to the pilot caregiver group. It ultimately offered this group of caregivers the opportunity to meet and share not only with health care providers, but with other caregivers dealing with similar issues and stressors. This type of caregiver education program enables caregivers to have a forum and open environment in which caregivers can problem solve together and obtain resources for taking charge of their own health *first* while secondarily preparing themselves for the challenges they may encounter with decisions related to their care recipient’s care longerm.

In hindsight, this pilot program was offered to caregivers living with those with stroke, brain injury, Parkinson’s disease, and multiple sclerosis. The next caregiver education sessions will be open to any caregiver caring for a loved one with any acute or chronic condition. While the pilot study supported the research hypothesis, opening up the program is one of the lessons learned that will service more Pennsylvanians dealing with caregiver burden whom need assistance. The program is also congruent with Health People 2020 goals and objectives in promoting health for all persons within the Commonwealth.

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**Appendix A: Individual Caregiver Results on the SF 12v2 Health Survey**

Pretest Data: January 11, 2017

RecordID	PF	RP	BP	GH	VT	SF	RE	MH	PCS	MCS	Gender	Agegender_PCS	Agegender_MCS
C1	100	87.5	100	60	75	100	87.5	75	55.62	51.88	M	At or above	At or above
C2	0	12.5	0	25	25	25	50	37.5	24.51	38.88	M	Far below	Far below
C3	25	0	25	0	0	0	0	0	34.83	14.18	F	Far below	Far below
C4	75	87.5	100	60	25	50	50	25	60.05	26.22	M	At or above	Far below
C6	75	62.5	75	60	25	25	75	37.5	50.72	33.35	M	At or above	Far below
C7	50	62.5	100	60	50	100	100	62.5	45.81	54.2	F	At or above	At or above
C8	100	75	100	85	50	100	100	75	55.2	52.57	M	At or above	At or above
C9	50	75	75	60	25	100	100	62.5	44.01	52.44	F	At or above	At or above

Posttest Data: February 15, 2017

RecordID	PF	RP	BP	GH	VT	SF	RE	MH	PCS	MCS	Gender	Agegender_PCS	Agegender_MCS
C1	100	100	100	60	75	100	87.5	87.5	55.89	54.04	M	At or above	At or above
C2	50	75	75	25	50	75	75	62.5	43.15	47.35	M	At or above	At or above
C3	50	37.5	50	25	50	25	87.5	62.5	34.73	47.35	F	Far below	At or above
C4	75	87.5	100	60	75	75	75	50	55.88	43.37	M	At or above	Below
C6	75	100	75	60	50	50	100	62.5	50.73	46.77	M	At or above	Below
C7	50	75	100	60	75	100	100	87.5	45.12	61.2	F	At or above	At or above
C8	100	75	100	85	75	100	100	87.5	54.25	57.42	M	At or above	At or above
C9	75	75	75	85	50	100	100	75	48.84	55.31	F	At or above	At or above

Abbreviation Key	
PF	Physical Functioning
RF	Role-Physical
BP	Bodily Pain
GH	General Health
VT	Energy/Fatigue
SF	Social Functioning
RE	Role-Emotional
MH	Mental Health
HT	Change in Health