



Using *Powerful Tools for Caregivers* in the Hmong community: Lessons from a demonstration project

The Amherst H. Wilder Foundation has been providing caregivers with personalized coaching, training, education, and support for over 15 years. In 2013, as part of an effort to expand caregiver services to diverse communities, Wilder replicated the caregiver education program, *Powerful Tools for Caregivers* (PTC), specifically for Hmong-American caregivers in St. Paul, Minnesota. This demonstration project, funded through an Innovations in Caregiving Award from the National Alliance for Caregiving and MetLife Foundation, was a collaborative venture of Wilder's Caregiver Services and Wilder's Southeast Asian Services.

Background

Powerful Tools for Caregivers is a six-week education program developed by Legacy Caregiver Services in Portland, Oregon. The program is based on the highly successful Chronic Disease Self-Management Program developed by Dr. Kate Lorig and her colleagues at Stanford University's Patient Education Research Center. The goal of the *Powerful Tools for Caregivers* program is to help family caregivers of older adults develop and practice self-care "tools" to thrive as individuals while managing caregiving responsibilities.

Each class is taught by a pair of trained facilitators who have attended a two-day training. Facilitators use a standardized curriculum that employs a variety of teaching strategies including didactic presentations, group discussion, brainstorming, modeling, role-playing, and action plans. The program is designed to serve 12 to 15 participants per six-week session.

Over a three-year period during which the original model was tested and evaluated, the program was shown to increase participants' self-care behaviors; ability to manage emotions including anger, guilt and depression; self-efficacy in coping with caregiving demands; and caregivers' use of community services.

PTC pilot program for Hmong-American caregivers

Wilder Foundation's objective in offering *Powerful Tools for Caregivers* to Hmong-American caregivers was to fill a critical, unmet need for caregiver education and support among the largest urban Hmong population in the United States. To provide this program, Wilder Caregiver Services partnered with Wilder's Southeast Asian Services Social Healing Center, a day program for adult Hmong-Americans designed to foster social relationships, decrease severe isolation, and enhance community belonging.

Program funding and partners

The PTC pilot project was supported by an Innovations in Caregiving Award from the National Alliance for Caregiving and MetLife Foundation, with additional funding provided by the Richard M. Schulze Family Foundation, and in-kind support from the Wilder Foundation.

A steering committee, composed of the Southeast Asian Services staff psychologist and two bilingual/bicultural staff from the Social Healing Center, Caregiver Services staff, and representatives from Wilder Research, met regularly over a one-year period to guide project development and implementation. In addition, Wilder consulted with Legacy Services, the creator of PTC, and the La Crosse County Unit on Aging in La Crosse, Wisconsin, which serves Hmong-American caregivers through similar programs. Wilder also collaborated with the Minnesota Department of Human Services and the Metropolitan Area Agency on Aging, which conducted the training for PTC leaders.

Outreach and participant recruitment

Outreach and recruitment for the pilot program was conducted primarily through the Social Healing Center's existing programs. Over 600 people are served through Wilder's Southeast Asian Services each year, a large number of whom are Hmong-American adults, providing a significant pool from which to recruit participants. Because Wilder staff had pre-existing relationships with these individuals and a level of trust had already been established, recruitment was less challenging than it would have been without these connections.

The program recruited 12 Hmong-American caregivers ranging in age from 40 to 63. Two participants were male and 10 were female. All were individuals with low incomes, and the program did not charge them a fee to participate. In addition, Wilder provided transportation, a meal, and childcare to enable caregivers to participate. The six-week program was held in February and March of 2013.

Implementation

The PTC pilot program was facilitated and led by two trained bilingual/bicultural social work staff from Wilder's Social Healing Center. They were assisted by a bilingual/bicultural intern, who provided help with interpretation and program logistics. The pilot used the 90-minute per class version of the PTC curriculum and added an extra half hour to each class to allow for the additional time required to conduct the program in Hmong.

Time and budget did not permit the translation of all materials, although assessments of care recipients' needs and caregiver distress were translated for paper and pencil administration in order to complete an evaluation of the pilot project.

Handouts and take-home materials were written in English. Staff delivered the program in the Hmong language based on their own translations from the English, but otherwise followed the program curriculum as written. This approach – first testing the program without modification to learn about its effectiveness with specific cultural groups before making changes – was recommended by the PTC replication guide.

Pilot program challenges

Recruitment. Many individuals did not self-identify as caregivers, which made recruitment challenging. There is a strong expectation in Hmong culture that family members care for one another at all stages of life, and many participants felt that they were only caregivers if they were getting paid (for example, through a Personal Care Assistant [PCA] program) to provide services. In addition, there is no direct translation for the word “caregiver” in Hmong, which made explaining the program to potential participants difficult.

Transportation. Wilder’s Social Healing Center has transportation services that were used for the program. However, without transportation, participants would not have been able to attend the program.

Group education model. Learning in groups is unfamiliar to Hmong individuals. Participants were more familiar with a hierarchical method of learning and expressed anxiety with having to share personal information with others in the group.

Culturally appropriate program materials.

- **Translations.** Wilder was able to access a few materials that had already been translated into Hmong, but not all materials were translated, and most participants did not read English.
- **Examples and role-play activities.** Several of the examples given in the PTC lessons were not culturally appropriate, especially role-play activities, primarily because they depicted scenarios that would not occur in Hmong culture.
- **Words that have no direct translation in the Hmong language.** Many common English words and phrases are difficult to translate into Hmong. For example, facilitators struggled to define phrases like “chronic disease” that have no direct translation in Hmong.

Understanding and completing the pre- and post-assessments. The assessments took a significant amount of time for participants to complete and added hours to the length of the program. Each participant needed individual assistance in interpreting, understanding, and completing the assessments. The PTC post survey was especially challenging for participants to complete because it asked them to reflect back on how they felt at the beginning of the program. Given the significant, complex challenges faced by participants, many of whom have experienced trauma, this reflection activity proved difficult. Also, the graduated scales of 1 to 10 used in the PTC post survey and participant satisfaction form were confusing for participants, and probably not culturally appropriate for this population.

Evaluation

Pilot program evaluation included pre- and post-assessments of caregiver well-being and a PTC post survey to measure program impact. Participants also completed a PTC program satisfaction form after the last class. In addition, a focus group discussion led by a Hmong-speaking facilitator was conducted with participants to gather qualitative data on the impacts of the program.

Results from the program assessments and focus group discussion indicate that participants benefitted from exposure to new ideas and ways to manage the stressors in their lives, and that the PTC material could be helpful in addressing current and future caregiving responsibilities.

Assessments

The PTC pilot program used three assessments to learn about participants' circumstances and the extent to which they benefitted from participating in the program.

1. The Live Well at Home Program Rapid Screen© (Hmong translation). At the beginning of the program, Social Healing Center staff administered the Rapid Screen© to all twelve participants as proxies for their care receivers. Scores for all participants indicated that their care receivers were at high risk for nursing home admission.
2. The American Medical Association's Caregiver Self-Assessment Questionnaire: How are YOU? (Hmong translation). The Caregiver Self-Assessment was administered and completed by nine participants both at the beginning and end of the program. At baseline, all nine participants reported scores that indicated a likely high degree of caregiver distress. At the conclusion of the program, seven of the nine participants had slightly lower scores, one had a slightly higher score, and one remained the same. Although none of the participant's scores indicated a statistically significant reduction in distress, seven of the nine moved in a desirable direction. While not definitive, this suggests that the participants likely derived some benefit from their participation, some relief from sources of stress, and potential new strategies for coping with stress.
3. The *Powerful Tools for Caregivers* program participant evaluation (English version). Social Healing Center staff administered the PTC program participant evaluation after the last session of the program. Ten participants completed the evaluation. However, the assessment form was not translated into Hmong and was instead administered orally (in Hmong) in a group setting. Because of this, and because there were some

concerns about how slight gradations of difference are perceived in the Hmong culture, researchers judged the quality of data not sufficient for rigorous analysis. Nonetheless, participants reported scores that suggest they may have felt somewhat more confident in their ability to take care of their own physical and mental health needs, manage their emotions, cope with caregiving demands, and get the help they need with their caregiving responsibilities.

Participant satisfaction and perception of benefit

The program gathered participant satisfaction and perception of benefit at the end of the program through the PTC class satisfaction form and a focus group discussion facilitated by Wilder Research.

1. PTC class satisfaction form. The satisfaction form was administered to ten participants at the last class session. Social Healing Center staff provided oral interpretations of the questions for the participants. All rated the overall program and the class leaders as “excellent” (9s and 10s on a 10-point scale). In addition, participants gave mostly “excellent” ratings to each weekly class, and none rated any of the classes “poor” or “fair.” Nine of ten participants also indicated that the class had provided them with helpful information about community resources.

Participants’ comments about what they liked best about the classes suggest that, for the majority, learning about ways to cope with the emotional challenges of caregiving and ways to take care of themselves were the most valued aspects of the program. Several participants also mentioned the opportunity the program gave them to socialize and share experiences with others as one of the best things about the program.

Some representative comments:

What I liked best about the program is identifying signs and reducing stress. And using positive self-talk.

Understanding – learning from emotions – dealing with anger, guilt and depression.

Positive self-talk and the support from others.

2. Focus group discussion. To learn more about how the program may have helped participants with their caregiving and how they thought it could be made more useful to them, Wilder Research facilitated a focus group discussion at the conclusion of the last class. Nine class members participated in the discussion, which was conducted in Hmong. The discussion showed that participants learned several things from the program that they thought were helpful. Notably, self-care techniques related to physical activity seemed to elicit the most positive responses.

Benefits reported by participants included:

- Learning about and practicing techniques such as walking and exercising to reduce stress and deal with anger and depression
- Learning and practicing more effective communication strategies for interacting with others (for example, asking people what they need versus making assumptions; being more patient; listening more carefully)
- Having time to build relationships with each other and offer mutual support
- Learning about community resources available to help them with caregiving

Participants felt strongly that providing all written materials in the Hmong language and using more visual aids were the most important steps the program could take to make it more helpful to those participating in future classes. They emphasized the particular importance of providing Hmong translations of take-home materials. They explained that action plans were an important part of the program and that if participants wanted to review what they should be practicing during the week, they would be better able to do so if the materials were written in Hmong.

Participants' comments and interactions during the focus group discussion clearly showed that they had enjoyed being part of the PTC group and had benefitted from contact with one another. It was also clear that not all of the discussion group participants thought of themselves as caregivers. They said, however, that they thought the techniques learned in the program were helpful to them now, and that they also intended to use them when they had other caregiving responsibilities in the future.

Lessons learned

1. All PTC program materials should be translated into Hmong, including take-home materials and pre- and post-assessments.
2. All materials should be culturally adapted for the Hmong-American community. Examples of cultural adaptations that need to be made include revising the script to use terms and concepts that are more readily understood in Hmong culture; changing the names of individuals used as examples to Hmong-American names; adapting role-play scenarios to reflect of Hmong culture; revising guided imagery language; and providing more visual materials.
3. Additional class sessions should be added to the program to allow more time for explaining and discussing the concept of caregiving and for completing required forms and assessments.
4. Using a trauma-informed approach to program activities may help avoid arousing painful memories and negative emotions on the part of participants. Many expressed feeling sad following the guided imagery exercises when they were encouraged to visualize a happy place. For many participants, their happy place – home – is intertwined with an experience of trauma.
5. The individual version of the PTC program may be a better fit for delivery to Hmong-American caregivers.

Since its inception in 1906, the Amherst H. Wilder Foundation, a 501(c)(3) nonprofit organization, has been committed to meeting the needs of vulnerable individuals and families throughout St. Paul, Minnesota. The wills of the Wilder family laid out a clear mission for the organization: *“To aid and assist the poor, sick and needy people of the City of Saint Paul...without regard to, or discrimination for any such persons by reason of their nationality, sex, color, or religious scruples or prejudices.”*

Wilder Research

Information. Insight. Impact.

451 Lexington Parkway North
Saint Paul, Minnesota 55104
651-280-2700
www.wilderresearch.org



AMHERST H.
WILDER
FOUNDATION
ESTABLISHED 1906

Here for good.

For more information about the PTC pilot program contact:

Maureen Kenney, Caregiver Services Program Manager
Amherst H. Wilder Foundation
650 Marshall Avenue
Saint Paul, MN 55104
651-280-2509 / maureen.kenney@wilder.org

For more information about the PTC pilot evaluation, contact:

Greg Owen, Senior Research Manager
Wilder Research
651-280-2714 / greg.owen@wilder.org

SEPTEMBER 2013