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Evaluation of the Powerful Tools for Caregivers Diversity Program:
Dissemination Successes and Challenges

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Acknowledgments

Executive Summary

Since 2004, the Erie County Caregiver Coalition (ECCC) has been offering Powerful Tools for Caregivers, a psycho-educational program for caregivers of older adults designed to reduce caregiver stress by improving caregivers' communication and decision-making skills and promoting self-care. This report describes 'lessons learned' from the agency's efforts to disseminate the program to African American, Hispanic, and Native American communities in their service region between 2008 and 2012. During this period, the Erie County Caregiver Coalition (ECCC), in collaboration with the University at Buffalo, was funded by the Health Foundation for Western and Central New York. The main goal was to increase diversity among participants in Powerful Tools for Caregivers classes by recruiting and training class leaders and facilitating the running of Powerful Tools classes in African American, Hispanic, and Native American communities.

This report describes a qualitative evaluation of these dissemination efforts. It addresses three topics: 1) needs and challenges faced by caregivers in the target communities; 2) potential for the Powerful Tools for Caregivers program to address these needs; and 3) dissemination strategies used, results, and additional dissemination strategies recommended for engaging advisory council members, class leaders, and participants.

Findings from the evaluation provide examples of dissemination challenges and strategies that may be applicable to other outreach efforts in the Erie County region.

Key findings

1) There is need for caregiver support in the three communities that is exacerbated by:
    - Lack of financial resources
    - Inadequate health care coverage for respite care
    - Lack of informal support from other family members
    - Difficulty seeking support; lack of trust in professional respite caregivers
    - For Spanish-speaking individuals, lack of Spanish-speaking professional respite caregivers

2) Participants' and class leaders' experiences with the Powerful Tools for Caregivers program were overwhelmingly positive. Many viewed their experiences as transformative. The program addresses several of the identified caregiver needs and challenges.

3) A wide variety of recommended approaches to disseminating the program were used:
    - Involving local community leaders and organizations in raising awareness about the program
    - Advertising in ethnic-specific media
    - Reducing barriers to participation such as cost and offering the program in convenient and familiar locations
    - Offering the program in participants' first language, culturally tailoring promotional materials, and culturally matching personnel (i.e., class leaders) and participants
    - Involving community representatives in an advisory capacity

- Building a trusted presence in the community through participation in community events and outreach

4) Factors that may have contributed to difficulty disseminating the program include:
- A need for staffing resources exclusively dedicated to relationship building and doing outreach in the target communities
- Too few personnel resources to engage three different minority groups
- The program required a substantial time commitment by class leaders, participants, and class venues
- Success may have been impaired by difficulty identifying volunteer class leaders experienced in doing community education or outreach
- Some class leaders may have needed intensive logistical support
- Due to national program restrictions, class leaders and advisory board members were not compensated for their time, which may have undermined their commitment

Introduction

Goals of the evaluation

Access to physical and psychosocial health promotion programs remains lower in minority than white communities. Agencies and community organizations need information, strategies and examples that will help them improve program dissemination in these communities. The purpose of this report is to describe findings from a qualitative evaluation of a Health Foundation for Western and Central New York -funded effort by a coalition of agencies to disseminate a psycho-educational program to African Americans, Hispanics, and Native Americans living in their service region. Overall, the goal of this report is to contribute to efforts to identify best practices for disseminating evidence-based psycho-educational programs in minority communities. Specifically, we sought to answer the following questions:

1) What are the caregiving challenges faced by African Americans, Hispanics, and Native Americans in Erie County and surrounding areas?
2) Does the program that was offered, Powerful Tools for Caregivers (PTC), address some of these challenges and needs?
3) What were the dissemination strategies used by the agency to promote and implement the PTC program in African American, Hispanic, and Native American communities?
4) What were the challenges faced when trying to promote and implement the program? Specifically, what were challenges to engaging advisory council members, class leaders, and class participants?
5) What strategies either helped overcome these dissemination challenges, or were suggested by members of these communities to help overcome these challenges? Specifically, what are potentially successful strategies for engaging advisory council members, class leaders, and class participants?

The Powerful Tools for Caregivers program: Background

The goal of the Powerful Tools for Caregivers (PTC) program is to help non-professional caregivers of middle-aged and older adults with chronic disease or disability better cope with caregiver strain. The program provides 15 contact hours with two trained facilitators who lead two and a half hour long classes once a week, for six consecutive weeks. The primary objectives of the PTC program are increasing participants' ability to identify, prioritize and meet their own psychological and physical needs and increase their confidence in their caregiving abilities. Participants learn how to communicate more effectively, improve their decision-making skills, and learn how to access support and resources. Examples of class topics are, "taking care of you," "identifying and reducing personal stress," and "mastering caregiving decisions". The delivery of the class content is highly scripted, but the class format allows for class discussion during which participants and class leaders share their personal experiences and challenges. Participants also receive a book with parallel content. Class materials, including the participant book are available in English and Spanish. Changes to the curriculum are dissuaded and require permission from the licensing agency. The program follows a train-the-trainer model and is lead by individuals who have participated in a two-day class leader training program conducted by master trainers. There are currently four master trainers in the Western New York area.

The PTC program is taught nationally and evaluations have demonstrated that participation in the program reduces caregiver stress,[1,2] and is associated with reductions in health-risk behaviors and improvement in self-care and psychological well-being.[3] Furthermore, the program is an adaptation of the widely evaluated and successful Chronic Disease Self-Management Program designed by Lorig and colleagues.[4,5]

Powerful Tools for Caregivers in Erie County

The Erie County Caregiver Coalition has delivered PTC classes in Erie County since 2004. Approximately 100 classes have been conducted, reaching over 750 caregivers. During this time, ECCC recognized that few minorities were being served by these classes and wanted to deliver the program in a targeted way to African Americans, Hispanics, and Native Americans. In collaboration with the University at Buffalo, ECCC applied for, and received, a grant in 2008 from the Health Foundation for Western and Central New York, (then Community Health Foundation of Western and Central New York) to create a sustainable infrastructure for delivering PTC to the African American, Hispanic, and Native American communities in Western New York. The intention was to train 12 class leaders and graduate 144 caregivers from the program. What is referred to as the diversity program was originally funded with a two-year grant; however, the granting period was extended to five years and ended in December, 2012.

Overview of outreach strategies

Advisory council

Early in the granting period, the PTC master trainers established a diverse advisory council. Using social network contacts, the program leaders at ECCC involved community leaders and professionals working in healthcare who could provide insight into best strategies for disseminating the program to the three target communities. Fourteen individuals participated to varying extents in the advisory council, which met a number of times early on in grant period. The advisory council provided input on promotional materials, the choice of incentives, dissemination strategies, and recommendations for, and assistance building relationships with the target communities. Some advisory council members such as clergy at churches that offer services in Spanish were recruited to the advisory council with the hopes that they would help promote the program within their respective communities.

Relationships established prior to receiving funding

The PTC program, including the diversity program, is administered through central registration and training coordination at Erie County Senior Services by two Senior Services staff members as a small component of their job responsibilities. Prior to receiving the grant, ECCC had developed relationships that they hoped would facilitate dissemination in the target communities. The Seneca Nation had committed their support for the project; two African American class leaders, one of whom was a master trainer (trainer of other class

leaders), were already conducting classes; and a Hispanic Erie County employee had been involved in developing the grant and was to do outreach in the Hispanic community. Exemplifying the fragility of relationships with community members and organizations, the relationship with the Seneca Nation dissolved because of a change in its elected government. In addition, the Hispanic colleague who was to act as a liaison to the Hispanic community moved to another city. Due to this, the ECCC program leaders were required to find alternative strategies for creating relationships with the Hispanic and Native communities. They also needed to expand their presence in African American communities.

Cultivating additional community contacts

During the early part of the granting period, ECCC sought to create relationships with community leaders who could help them identify class leaders. African American class leaders gave testimonies about the effectiveness of the program and Pastors and First Ladies were asked to help identify class leaders and hold classes in their churches. Three classes were ultimately held at African American churches. Through social networks, program leaders identified and approached two priests neighborhood churched that offer services in Spanish. ECCC initially tried to work with NACS (Native American Community Services of Erie & Niagara Counties, Inc.) to attempt to offer classes to Native Americans. The director of NACS identified two individuals to be trained as class leaders; however, these recruits did not go on to participate in the training. Other class leaders were identified from within ECCC, and through chance meetings with ECCC members at community events.

Cultivating relationships, support, and trust in communities is challenging. As ECCC encountered difficulty identifying class leaders, scheduling and running classes, they sought input from the advisory council and hired a cultural consultant to advise them on dissemination strategies. The cultural consultant delivered a cultural competency assessment and recommendations in April, 2010. They also hired a consultant from the Tuscarora tribe to help them gain entrée into the Native community. This person ultimately recruited 5 Native American class leaders, including two individuals from the Tonawanda tribe and two from the Tuscarora tribe. A sixth person who is Hispanic, but had worked at NACS, also joined this group. The Native American consultant also facilitated a meeting between one of the ECCC project leaders and the chief of the Tuscarora tribe. Two of the class leaders from this group held a class at NACS. The Native American consultant also facilitated meetings with local tribal governments, which allowed the program to be brought into tribal territory. Near the end of the granting period, in the summer of 2012, program leaders also hired an African American consultant to help recruit African Americans into the program. Ultimately, it was felt that this effort was unsuccessful.

Throughout this period, master trainers participated in a wide variety of events such as health fairs in the Hispanic and African American communities in order to raise the profile of the PTC program. The ECCC project leaders also attended a workshop offered by NACS to introduce people to Native culture and history. Through the workshop, ECCC project leaders learned about the detrimental impact of boarding schools on family structure and individual psychology as well as the importance of offering food and blessings at community events. They incorporated what they learned into the class leader training for Native class leaders and their understanding of caregiving in the Native community.

Dissemination results

Seven classes were held as a result of the diversity program, including four classes in the African American community, one class held at Los Tainos, a Senior Citizen's Center that serves primarily Hispanic clients, another at Shalom Zone, a center that provides social services, again to primarily Hispanic clients, and one class conducted at NACS. Two African American class leaders were involved with PTCG prior to the inception of the diversity program. Five more African American class leaders were trained, along with five Hispanic and seven Native American class leaders (one of whom was Hispanic but had worked at NACS) for a total of 19 new class leaders. Six of the seven African American class leaders taught at least one class; two of the five Hispanic class leaders lead diversity program classes and one taught a class outside of the diversity program; and one of the six Native American class leaders and the additional individual who had worked at NACS taught a class. Thirty-four participants took part in the classes.

Evaluation Methodology

Sampling strategy and participant recruitment

A total of 28 respondents were interviewed. An initial list of all advisory board members, master trainers, and class leaders involved in the PTC program was obtained from the program coordinators on March 23rd, 2012. This list served as the initial sampling frame. We also interviewed a grant program officer. Each potential respondent was invited to participate via email or telephone. Of the 30 potential respondents, we were able to contact 26 individuals. Twenty-two participated in the evaluation (85% of those invited). We were also interested in reporting on the perspectives of class participants. To generate a list of potential respondents, we asked class leaders who had held diversity classes to recommend individuals who had participated in their classes. To maintain confidentiality, class leaders obtained each individual's permission to forward their contact information to the evaluation team. Using this snowball sampling strategy we were able to recruit 6 class participants. Data were collected from February 2012 to September 2012.

Procedures

There were three interviewers on the evaluation team, and interviews were conducted at respondents' workplaces, the University at Buffalo, and respondents' homes. The evaluation was IRB approved, and each respondent signed a written informed consent document. The semi-structured in-depth interview began by asking respondents how they had become involved with the PTC program. Interview questions focused on respondents' experiences with the PTC program, their knowledge of and involvement in disseminating the PTC program to diverse communities, their perceptions of caregiving in the three target communities, and respondents' recommendations for future dissemination initiatives. Interviews lasted between 30 minutes and 2 hours. All interviews were audio-recorded and later transcribed verbatim. Interviewers wrote detailed observation notes, experiences with the respondent before and after the recorded interview, and non-verbal aspects of the interview. Observation notes were added to interview transcripts to form complete data files.

Additional data

In addition to analyzing interview data, the evaluation team reviewed materials used to promote the classes and the cultural competency assessment compiled by the cultural consultant in 2010. They attended a meeting with the consultant who was hired to conduct outreach in the African American community and African American class leaders. They also corresponded regularly with program staff.

Data analysis

An initial list of codes was developed based on the interview guide, major research questions, a review of the literature, and major emergent concepts in the data noted in a

careful read of each interview transcript by two members of the research team. This process yielded 17 broad data-driven codes (such as "caregiver challenges" and "dissemination barriers"). Two members of the research team independently read and coded each interview. Discrepancies were resolved through consensus. Coded data were entered into the qualitative data analysis program NVivo. The lead researchers then performed a more fine grained analysis of the coded text, identifying themes within the overarching codes. Thematic analysis was conducted and attention was paid to code frequency, code co-occurrence, and the context and meaning of codes for groups of respondents.[6]

Results and Discussion

Need for caregiver support in the African American, Hispanic, and Native American communities

Caregiving burden

Within the African American, Hispanic, and Native American communities, there are cultural norms that prescribe caring for the elderly or disabled at home by family members and dissuading people from putting family members in nursing homes. One Native American respondent said, "You don't do that here. Somebody takes care of them." Similarly, in the Hispanic community, "Latinos believe in keeping their people at home and caring for their people at home." Members of the three communities have deep-seated reasons for not utilizing formal sources of caregiving support such as agencies, organizations, hospice, or nursing homes. A Hispanic respondent explained,

> "It could be tradition; it could be mistrust; it could be feeling of responsibility, this is my responsibility; I need to do this. My parents, or whoever it is, took care of me all their lives and now I have to take care of them."

In this respect, because members of the three groups are more likely to be doing intensive caregiving, the program may be valuable to a relatively larger proportion of the population.

In addition, data from interviews provided evidence that among caregivers, burden could be significant, if not overwhelming. As one participant described caregiving, "When you are taking care of someone it takes your whole life and I think a lot of times people get to the point where they feel there is nothing else." The PTC program is a good match for people who are experiencing caregiver stress because it is focused on improved self-care, coping, and stress reduction in caregivers.

There were a number of specific caregiving challenges discussed by respondents that were noteworthy and are described below.

Caregiving challenges
Financial strain

Having inadequate financial resources increases the stressors faced by caregivers and makes it more difficult for them to mitigate caregiver burden. As one class leader summed up the situation, "If you're economically challenged, there's only so much you can do." Respondents discussed not being able to afford as much respite care as they needed. It was mentioned that for those relying entirely on government benefits for respite care, these benefits were inadequate. On the other hand, those with "a good job" may still find it hard to afford respite care because they have to cover the cost entirely by themselves. In addition, inadequate financial resources makes it more difficult and stressful to do caregiving in other ways; for example, not being able to afford a vehicle makes it challenging to take the person one is caring for to medical appointments.

Language barriers complicate respite care

Inability to hire or be assigned Spanish-speaking respite caregivers was perceived as a significant barrier to adequate support for Hispanic caregivers. In addition to simply making coordinating respite care challenging, the language barrier makes trusting respite caregivers more difficult.

Role exhaustion

A commonly mentioned challenge for caregivers is being overwhelmed by competing responsibilities. In addition to caregiving, many caregivers are likely to be working outside of the home, and women, who were most often functioning as caregivers, are likely to be caring for other family members and managing household responsibilities in addition to their work and caregiving. Respondents from all three communities remarked on the toll caregiving takes on people who are juggling multiple roles. Several respondents remarked on how caregiving had become more burdensome than it was in the past because now, unlike for previous generations, women are working outside of the home. An African American respondent observed,

> [Historically] "I would think a lot of the women didn't work. They didn't work outside of the home so they were there and they could do that. But now, with people having to work and take on this responsibility too, it's a lot."

A member of the Native American community echoed this observation:

> "I think it's getting more challenging because you're having both parents working now, where I think a generation ago a lot of times you had one, typically the mom was home."

Balancing careers outside the home, household responsibilities and child care with caregiving responsibilities can be a challenge and burden for caregivers. These competing responsibilities can compound the stress caregivers experience.

Unequal caregiving burden and lack of social support

Exacerbating the situation, many caregivers experienced inadequate informal support. Respondents believed that a number of factors contributed to inadequate social support for caregivers. Caregiving may not be distributed equitably across family members. Some caregivers encountered reluctance on the part of siblings and other family members to contribute. One participant recalled, "I was reaching out for help and I wasn't getting any help from my sister or my brother and everybody was off doing their own thing and it was like everything had fallen on me." In other instances, the burden fell on the person who did

not work or worked less. One respondent described a caregiver's experience, "She's got two sisters, but they both work. She really carries the load (for) them."

It was believed that, to some extent, lack of support from family members reflects cultural shifts. Respondents from all cultural groups remarked on generational changes in attitudes toward caregiving that had reduced the availability of family support for caregivers. One Native American reflected, "Unfortunately these days the younger people are more about themselves." This was echoed by an African American participant, "Nowadays the kids just don't have time for, they don't take on responsibility like they should."

Of the three groups, African American caregivers may find themselves with the least informal support. Although perhaps declining, Hispanics and Native Americans reported that it was still common to have family support. One Native participant remarked, "Within the community, everybody takes care of each other, whether you're family or not." A Hispanic participant emphasized that caregiving was done collectively by large, extended families:

> "The Hispanic community is a lot more bound to the family nucleus. It just does not break. So we don't need a lot of support maybe from outsiders because I can have my two brothers, my sister in laws, my children, everybody's involved in the care. I am not alone."

Caregivers who have access to this informal support may experience reduced burden in their caregiving role. However, respondents believed that this informal support is less common than it may have been in the past.

Difficulty seeking support

Respondents noted that despite being under significant strain, caregivers often have difficulty asking for help, accessing resources, or simply prioritizing their own needs. While in the midst of caregiving, people can be reluctant to seek help: "People just don't believe they need the help. And sometimes people are embarrassed and they don't want to let people know how stressed they really are." They may not seek support because they do not recognize the strain that they are under. One person who had cared for her mother said, "I didn't realize how much I was carrying until it was all done."

Lack of trust in professional caregivers

Finding themselves in a situation where informal support is sometimes lacking, it was nonetheless difficult for many caregivers to seek paid respite care. This was echoed across all three cultural groups. In addition to cost, caregivers' primary concerns were that professionals would not care for their loved ones as well as they did. They worried about the quality of the care and whether it was personal enough. One participant talked about a friend: "If we went to Canada and she wanted to stay overnight she said no, I've got to get back. Because [someone else is] watching him and I don't know if she understands this about him." Respondents from the African American and Hispanic communities talked about the difficulty of trusting respite caregivers in your home. One class leader told us about her neighbor, "Well. I don't want everybody in my house and you know, they're not going to do it like me." There are few Spanish-speaking respite caregivers, so for Hispanics

who speak little English, the language barrier makes it even harder to trust professional caregivers.

Some diseases and disabilities pose unique challenges

Finally, the types of disability that families are dealing with contribute to caregiving burden. In the Native American community, where diabetes is common, people are sometimes caring for people who have had limbs amputated and who may need to be lifted: "With diabetes being such an epidemic amongst our people, you get into amputee situations, things like that, where it's very difficult to keep somebody at home." Under these circumstances it was especially challenging or even impossible for the family to care for the person at home. Another situation that people noted as being especially difficult was caring for someone with dementia who had experienced negative personality changes, or had become uncooperative.

Caregiving challenges: Summary

Respondents described significant caregiver burden, inadequate support, and reticence to seek support. The PTC program is focused on helping caregivers identify their needs, improving their support-seeking skills, and making prioritizing needs normative; therefore PTC potentially addresses some of the root causes of caregiver strain in the three target communities.

Table 2. Caregiver Challenges Major Themes and Implications for Dissemination

Major themes
1) The African American, Hispanic, and Native American communities likely experience significant caregiver burden.   2) Caregiver burden is exacerbated by lack of financial resources; inadequate health care coverage for respite care; lack of informal support from other family members; difficulty seeking support; lack of trust in professional caregivers.
Implications for dissemination
1) PTC addresses several core caregiving challenges identified by respondents; therefore, has potential for effectiveness in the three target communities.

Benefits of the Powerful Tools for Caregivers program

Respondents reported numerous important benefits of the PTC program. Many respondents experienced these benefits personally, and the program shaped their own experiences as a caregiver. Others observed these benefits through their involvement with the PTC program. Several broad themes emerged in the perceived benefits of the PTC program.

Passionate belief in the power of the program

An overarching theme in interviews was a central belief in the transformative power of the PTC program. Respondents felt deeply that this program works, is important, and changes lives. One respondent explained,

> "It was the most phenomenal class I think that I've ever taken. It was life changing for me. It was really a godsend. I think the parts that were most helpful to me was knowing I'm not alone…Sometimes when I find myself just instantly, I get overwhelmed and I'm able to remember what I learned in class and just like, okay, this is it. And remember some of those tips and tricks and information and things, ways to deal with situations that I learned in the class. It calms me down so that my blood pressure doesn't go through the roof, so that I'm not disrespectful because she is my mother and will always be no matter what the situation is and I don't want to ever be disrespectful to her. And so I'm able to take care of the situation, maintain my respect for her as my mother and as a human being and keep myself calm. Sometimes I mess up, but I'm so much better than what I used to be."

Respondents believed that the PTC program has important benefits that are relevant to the needs of all caregivers, including those from the African American, Native American, and Hispanic communities. Many respondents were very proud to be a part of the PTC program, which they passionately believed in.

Encourages beliefs and skills that promote self-care in caregivers

A primary goal of the PTC program is to promote self-care and support-seeking in caregivers. Respondents reflected on the power of encouraging caregivers to take time to care for themselves.

> "I liked the part when they sort of taught the people how to take care of themselves. Go get your hair done. Take a break. Go to a movie, even if you go alone. Just take a break from where you are constantly with this caregiving. And that's going to give you more strength to come back and do what you're doing, you know. Go to lunch with a friend or something. I thought that was one of the great parts about it."

Respondents who had participated in the PTC program described these self-care strategies as transformative, and respondents who were class leaders reflected on observing the benefits class participants experienced as they adopted these strategies.

Respondents believed that one of the greatest strengths of the PTC program is its focus on reducing guilt felt by caregivers when they take time to nurture their own physical, mental, and emotional health. While class participants formerly may have felt selfish taking time to enjoy a hobby or other activity, the PTC program reoriented their thinking. The PTC program emphasized that to be a better caregiver one must take time to care for oneself. Respondents believed that the PTC program is successful at this. Participants and class leaders discussed how they had become more assertive in taking time for themselves and getting help. Respondents talked about learning to give themselves permission to take care of themselves. As one participant put it, "to really learn that before you can take care of another person, you have to take care of yourself… you need time for yourself so you can be a better caregiver."

Provides social support and encourages social support seeking

The PTC program also offered an important source of social support for participants. Through the PTC program, caregivers were able to connect with others in similar circumstances. These connections offered support, coping strategies, practical advice, and camaraderie. One respondent explained,

"It was really just being with other people who were going through the same thing and being able to talk about it freely and openly and just knowing that other people understood and that I'm not alone."

Another respondent reflected, "Just being able to equip people on how to handle things because sometimes they think they're alone and in reality they're not alone, you know? There are things that they can do." For some, participating in the program was the first time they were able to find support from people who understood the caregiving experience and could provide non-judgmental social support.

The program also offers participants strategies and skills for eliciting social support: "And now there might be other siblings, but the siblings don't want to help. Or maybe they do want to help and you just don't know how to communicate that to them. We give them those tools." The PTC program offers participants strategies to mobilize their support networks, and increase the help available to them.

Normalizes negative caregiver experiences

Class participants found that sharing caregiving experiences with one another helped normalize negative experiences, and diffused associated negative emotions such as guilt, shame, and anger. Examples included normalizing lack of support from other family members, or negative personality changes affecting the person for whom they are caring. One participant said, "Everybody was doing their own thing. I couldn't understand that, that was Mom. But I learned later, that's life. It happens. And I found out that I wasn't the only

one, so I guess that's normal." The PTC program affords participants the opportunity to connect with other caregivers, and through these connections learn that their experiences are common to the experience of caregiving.

Increases information about caregiver services

The PTC program also connected class participants with information about additional services in their communities that may offer assistance in caring for their loved one. As one respondent described, these services were often extremely helpful for caregivers:
> "I think it's a great fit especially because it's giving you the tools for the ideas for how to do things easier for you and also better for you. It will also give you information about services that are out there, that sometimes people have no idea that even exist."

This access to additional information and sources of support was perceived to be a great strength of the PTC program.

Encourages new ways to view the role of caregiver

The PTC program also offered respondents a way to conceptualize their roles as caregivers. The PTC program offered participants a language and framework for thinking about their roles as caregivers, which allowed them to take advantage of the support and coping strategies offered through the program. It might also increase the likelihood that caregivers will use the caregiving-related services that they learn about in the program. This new conceptualization and labeling of their roles as caregivers also allowed participants to acknowledge and develop strategies to cope with the sometimes difficult and conflicted emotions they experienced related to their responsibilities as a caregiver. In particular, the PTC program helps participants move beyond feelings of guilt when they felt conflicted about their role as a caregiver. They also learn that guilt and conflict are common feelings associated with caregiving.
> "It helped [class participants] bring out some emotions that they were then dealing with. Of course we have tissues there and we need them at times. And a lot of times people don't realize that they have all this emotion bottled up and a lot of anger and guilt and frustration, you know? So we bring those things up so they can see, and most of them have the same problem, the guilt, the frustration, the anger, the loss of freedom, themselves, because you have to realize if you're taking care of someone that's ill, not only that person has lost their freedoms, but so have you, the caregiver have lost their freedom. And the things that they can't do anymore, like go on vacations. Or even the anger where they had planned to do these things and now the plan is dead."

In addition to strengthening some individuals' identification as a caregiver, the PTC program helps others redefine their caregiver self-concept in a more positive light, increasing

their self-efficacy for caregiving and their sense of control over the situation. A class leader observed,

> "At the beginning they were a little bit apprehensive, but then when they continued learning about the process and saw that they were not alone, there were other people. They noticed that it's okay, it's not my fault, there's something I can do about it."

The PTC program encourages participants to recognize their role as a caregiver, and offers a language and way of thinking about this new role. This focus allows participants to form a new framework for thinking about the important role they play in being a caregiver, the support of others in a similar circumstance, a focus on self-care, and tools to increase the support available to them.

Views of the Powerful Tools for Caregivers program: Summary

Respondents passionately believe in the importance and relevance of the PTC program. The program teaches practical coping skills that help caregivers in important ways. The PTC program also offers social support, which aids in emotional coping, normalizes the negative caregiving experiences, and provides information and resources. Finally, the PTC program reframes the role of the caregiver, and encourages caregivers to take time to care for themselves.

Table 3. Benefits of the PTC Program Major Themes and Implications for Dissemination

Major themes

1) PTC is an important program that offers caregivers critical skills and resources.
 	
2) PTC fills important coping needs of caregivers, including:
    a. Offering practical coping strategies.
    b. Encouraging beliefs and skills that promote self-care in caregivers.
    c. Social support and connections with other caregivers.
    d. Normalizing negative caregiver experiences.
    e. Informing participants about additional services that may provide further support to caregivers.
    f. Offering alternative ways to view the role of the caregiver that may help participants integrate the notion of caregiver into their identities and increase their confidence in their abilities to cope with negative consequences and emotions associated with caregiving.

Implications for dissemination
 1) Marketing that conveys past participants' transformative experiences may enhance participant recruitment. 2) Marketing that highlights positive outcomes as identified by class leaders and past participants (e.g., social support, sharing experiences, learning about resources) may resonate with the target audience. 3) Specifically, participant testimonials given at community events by participants who can speak about their positive experiences may be an effective marketing strategy for recruiting participants. 4) Word of mouth marketing through social networks may be especially effective at communicating the benefits of the program for past participants. In order to capitalize on positive interpersonal communication about the program it may be necessary to encourage this overtly (e.g., attendees may be given cards advertising the next class to hand out to friends and family), as well as have regularly scheduled classes for people to attend.

Dissemination strategies and recommendations

Engaging the advisory counsel and contributions of the advisory council

Members of the advisory council were primarily involved early on in the grant period, perhaps the first 2-3 years, and to varying degrees. Advisory council members recalled that the meetings functioned well. The program staff believed that the advisory council contributed significantly to the program and was especially appreciative of the input that they provided on culturally tailoring promotional materials for the program and dissemination strategies. Two challenges of having an advisory board bear mentioning. The first is engaging advisory council members. The community and agency leaders that are a natural fit for an advisory council tend to be busy, if not over-committed. ECCC faced challenges in encouraging attendance at meetings, involving advisory board members in promoting the program in their respective communities, and delivering promised resources. The second challenge is finding ways to integrate conflicting input from different members of the council.

Opportunities for engaging advisory council members

Unless they played a second role in the program (e.g., class leader), at the time of the evaluation, the role of advisory council members was minimal or they were no longer involved. Most knew little about the status of the project. A small minority were not currently aware that they had participated in the advisory council. Few recalled the content and goals of the PTC program unless they played another role and some were confused about their role and responsibilities as advisory council members. They did, however, hold positive attitudes toward the program or the general idea of providing an educational program and support to caregivers.

The advisory council may have been underutilized as a resource for helping with dissemination. It might be necessary for funding to be allotted specifically for engaging the advisory council (and class leaders). This might be used to fund personnel to provide more regular communication (e.g., email and meetings) with advisory council members about the status of program dissemination, provide follow-up when advisory board members have volunteered resources, and pay advisory council members for their time.

Engaging the advisory council: Summary

The advisory council presents an opportunity to build and strengthen relationships with community members and key stakeholders and gatekeepers. However, building meaningful and sustained relationships takes a considerable amount of time. Investing resources specifically allocated to building relationships and managing communications with advisory council members may be helpful for keeping members engaged.

Table 4. Engaging Advisory Council Members Major Themes and Implications for Dissemination

Major themes
1) The advisory council was perceived as contributing significantly to the cultural tailoring of the dissemination process. 2) Building and sustaining relationships with advisory council members takes a considerable amount of time and resources. 3) The advisory council might have been more consistently engaged over time. 4) Advisory council members might have played a larger role in promoting PTC in their respective communities.
Implications for dissemination
1) To more fully engage an advisory council or community partner, establish regular communication with members, including detailed information about the program goals and content, regular progress updates, and opportunities for involvement in dissemination efforts. 2) Resources may need to be requested to support a staff member who takes on these activities as his or her primary job responsibilities. 3) It can be challenging to integrate the contributions of multiple advisory council members. It may be helpful to have procedures in place to ensure that decision-making processes are transparent and collaborative.

Engaging class leaders

Strategies employed to identify and recruit class leaders

We asked respondents involved in the dissemination of the PTC program how they identified and attempted to recruit class leaders from the African American, Hispanic, and Native American communities. There was an early attempt to identify class leaders through formal relationships with other agencies that had supported the grant submission. In some instances these connections were not fruitful, or in a couple of instances, the individuals identified did not attend the class leader training. . Respondents commented that attempts to identify class leaders through the African American clergy and clergy in churches conducting Spanish services were largely unsuccessful. In contrast, professional networks were a primary source of identifying and recruiting class leaders. A number of class leaders were identified through agencies and others through chance encounters at professional or community events. Several respondents became involved because they had a direct connection to master trainers. When asked how they became involved, one respondent explained, "(master trainer) called me to see if I can be involved." Another successful approach to identifying class leaders was to partner with someone within the community who identified and approached individuals who were invited to be class leaders. One respondent explained, "One of the members of my church said that he knew some people that were starting a committee that he thought I would be good on and he gave them my name." This approach was successful at recruiting Native American class leaders. ECCC hired a consultant who was highly connected in several Native communities. Six individuals, including five Native Americans were recruited and trained as class leaders as a result.

Characteristics of successful class leaders

An overarching theme that emerged from the data was that the job of a class leader is difficult, and recruiting highly talented and committed class leaders is a core dimension of the success of the PTC program. Respondents identified numerous qualities of successful class leaders. These qualities included:

- Someone who understands caregiving and the feelings of caregivers

- Someone who is involved in the community and who can use their social network to recruit participants

- Someone the community trusts

- Someone who is outgoing, a good communicator, and a dynamic presenter

- Someone who is open and honest

- Someone who is non-judgmental and does not talk down to class participants

- Someone who is able to manage the conversation – both able to draw people out if they are reluctant to talk in class but also knows how to bring people back to the class material

- Someone who really understands the purpose of the program, what is expected of them before they commit to being a class leader, and who is committed to and believes in the program

Supporting class leaders

Only a few class leaders were supported by their workplaces to conduct PTC classes; nearly all were conducting classes on their own time even though some held paid agency positions. Respondents reported that class leaders outside of the diversity program often teach the class on work time, but this was rarely the case for those leading the diversity classes.

Paying class leaders. Attempting to disseminate the program through a network of volunteer class leaders may present several challenges and require special considerations. First, due to the demands and complexities of the role of class leader, respondents from all three racial/ethnic groups believed that class leaders should be paid. Respondents felt that this would help recruit, train, and retain successful and committed class leaders. Respondents in the African American and Native American communities discussed the fact that those people who are civically minded tend to be spread thin because they carry most of the civic work. One respondent explained, "what you find in the Native communities is, a lot of times it's the same people doing the work. And so you just keep stretching the same people out more." Paying class leaders would reduce the burden on them. In addition, informants from each group mentioned that having a paid person in the community who is responsible for the program might be necessary for sustainability. While the national PTC program places restrictions on paying class leaders, future programs may benefit from greater compensation for individuals in similar roles.

Logistic support. The two staff members from Erie County Senior Services provided logistical support to class leaders. They met with administrators at prospective venues to introduce them to the program; they advertised the classes in newspapers and on the Internet. They also provided central registration for African American classes but not for Hispanic classes, anticipating responses from Spanish-only speakers, or for Native American classes, in order to limit the involvement of government in these classes. When using central registration, prospective participants called Erie County Senior Services, were registered for the class and were mailed a reminder letter about the time and location of their class. Some class leaders expressed the need for additional support with the logistics of running a class (e.g., finding a venue, planning, scheduling, and recruiting participants to the class). Organizing the class, especially trying to recruit participants, may be too large a task for volunteers, especially those who are doing it for the first time or who have not previously done community education or outreach. Some expressed a preference for a graduated introduction to these various responsibilities. One class leader reflected, " Probably, had I facilitated a class, I probably would have felt better about going out, reaching out to some of the people to see if they would be interested." Others felt confident with the level of support provided. Discussing the class leader training, one class leader recalled that, "They told us

how we could advertise the classes, and what equipment we needed, they gave it to us."
Some class leaders, especially, those who have worked within the context of a social service
agency may not require additional support.

That said, it can be difficult for the organizing agency to provide logistical support in
a community where it does not have a history of engagement. The master trainers did make
connections with community leaders, but reflected on the fact that this was more effective
when someone connected with the community functioned as a liaison for them. The
paradox and challenge for agencies doing outreach work in minority communities is that
community volunteers often need significant support; however, the agency often does not
have the cultural capital to be able to provide this support. For example, they do not have
existing relationships with community members that would enable them to initiate
scheduling a program in a community venue such as a place of worship.

Training Native American class leaders separately

Acting on the suggestion by the consultant for the Native American community, the
master trainers taught the second group of Native American class leaders as a separate
group. The consultant had emphasized the need for creating class leader trainings solely for
Native Americans because they could feel excluded if louder, more talkative cultural groups
were also participating: "Native communities are much more quiet initially, but once
relationships are formed, they're more invested." One of the respondents confirmed that
holding a separate training had been important and had made her feel more comfortable:
> "It was a comfortable environment because I knew (the trainers), and the
> other participants were also Native….But it made it more comfortable that
> way because the experiences you hear, you could related to because it was
> coming from the Native community."

Class leader successes

Cultural match with class leaders valued. The master trainers recognized the value
of pairing class leaders and participants along racial/ethnic lines, and for all diversity classes
at least one of the class leaders was culturally matched to the target community. Class leaders
and participants also placed considerable value on pairing class leaders and participants from
the same culture. For Hispanics, this was especially important because of the need for a
Spanish-speaking class leader. Also, a Native American class leader confirmed that it would
be important to pair a Native class leader with Native participants so that the class leaders
understand the participants' cultural experiences and are not judgmental.

Peer leader model successful. Respondents believed that the use of peer leaders is
effective. One class participant identified this as a strength:
> "I really did like the fact that our instructors or our facilitators were not
> really, they didn't make us feel like they were teachers. They really made us
> feel like they were really a part of the class, like they were right on our level.

They have an understanding of what we were going through. Those were the two best instructors you could possibly have for this class."

Similarly, another participant valued the class leaders for their supportiveness: "They seemed to be really sympathetic and they offered suggestions as well," which was perceived as coming from their own experiences: "I think they had their own personal experience working as a caregiver, because I just felt that they had been through it or been through something…It was coming from the heart."

Engaging class leaders: Summary

Respondents discussed the importance of identifying, recruiting, and retaining committed and effective class leaders. This was not always easy, as attempts to recruit class leaders through community leaders such as clergy, pastors, and community organizations were not necessarily fruitful. Perhaps exemplifying a more promising approach, a Native American consultant was able to recruit six individuals to be trained as class leaders. Interviews revealed that recruiting energetic, dependable, and capable class leaders and advisory board members is a key dimension of the appeal of the program to participants and success in scheduling classes.

Ideally the ability to be more selective when recruiting class leaders to ensure that those chosen have the time and commitment, and clear understanding of the effort necessary to schedule and teach a class may help in sustaining commitment from class leaders. Class leaders having some previous experience in community outreach or organizing may also increase the likelihood of success. However, there was not an opportunity to be more selective in this case because of the difficulties in identifying a large enough pool of potential class leaders. Alternatively, or in addition, the organizing agency may want to provide more support to class leaders.

Most emphatically, respondents felt that class leaders needed to be paid to offset the burden of organizing and teaching classes and that more help with the logistics of locating and scheduling a class would be helpful. However, due to the restraints from the national PTC program, this was not possible. Participants were unanimously pleased with their class leaders and valued the fact that they often shared their cultural background, and brought their personal experience with caregiving to bear on the class material and discussions.

Table 5. Engaging Class Leaders Major Themes and Implications for Dissemination

Major themes
1) Cultural match between class leader and class participants is valued.
2) Class leaders who had personal experience with caregiving are perceived to be more effective and committed to the program.
3) Being a successful and committed class leader is demanding.
4) Class leaders should be compensated.
5) Class leaders, especially those who do not have agency experience, or are volunteers, can find it difficult to organize the classes.

Implications for dissemination
1) Establish clear understanding of the program goals with people functioning as community liaisons (e.g., identifying class leaders) about the nature of program, skills and personality required for the program to be successful.
2) Develop techniques for recruiting to avoid recruiting people who did not understand the commitment they were making and are not deeply committed to the program. Ideally one would be able to implement a selection process for identifying class leaders.
3) Compensate class leaders.
4) If class leaders are volunteers rather than agency employees, they may need additional support with logistics of organizing classes and recruiting participants.
5) To develop support for the program over the long-term, continue to develop relationships with community leaders such as religious leaders in the African American community and tribal leaders in the Native community so that the program can be held where people are already active; however, in the short-term it may be necessary to hold classes in locations not requiring community entrée (e.g., libraries, senior centers, community organizations).
6) When training Native American class leaders it appears to be helpful to have separate training sessions for the group and emphasize the informal, conversational nature of the program sessions.

Engaging participants

Strategies used to recruit class participants

In addition to advertising the class on the Internet along with other PTC classes being held in the region, attempts were made to have pastors and clergy promote the program to their congregations. Advertisements were placed in local newspapers that have a high circulation in the target communities. Several class leaders also posted flyers advertising the PTC program around the community. In some cases, classes were advertised in church bulletins and through announcements made during church services. Respondents also mentioned trying to recruit friends and family through word of mouth. Many reflected on the limited success of these efforts. They felt that despite their efforts to raise community awareness about the PTC program, they had not been successful. Many respondents believed that there is little knowledge of the PTC program in their communities. One respondent explained, "I think the familiarity with this particular program is so low that I would say just about not familiar with this program at all."

Dissemination barriers

Time intensive nature of recruitment

Efforts to recruit racially and ethnically diverse caregivers to participate in the PTC program encountered several key dissemination barriers. One difficulty was the large amount of time required to foster personal connections with potential participants. Word of mouth advertising is time intensive, and few personal connections resulted in individuals enrolling in the PTC program. This meant that a lot of time is invested to produce incremental results. One respondent reflected,

> "I had several people talk to me about it on East Utica street. I sat down with one elderly lady and explained the whole book to her, you know, the course, certificate, the pictures, the whole 9 yards. Where they are going to go with it from there, you know, I can only talk to the person but I can't lead the horse to water."

These experiences were common for individuals who engaged in word of mouth advertising. While it was perceived as the most effective method of recruitment, word of mouth advertising also required a large amount of time spent discussing the program without the guarantee of successful recruitment of class participants.

Lack of clarity about the core mission of the program

Although some class leaders were very clear about the purpose of the program, others may not have been. One class leader did not understand the nature of the program when agreeing to be a leader – the person thought it was a program where class leaders would be working with those needing care. Another class leader promoted the class as something that might lead to employment in home healthcare: "I made a poster, and the girls were saying, this is good, I can get a job out of that! So that really worked." Master

trainers recognized that this was a potential issue and stressed the mission of the PTC program in all communication with class leaders and the public. However, despite these efforts, confusion about the core purpose of the program existed.

Failing to generate an accurate conception of the content and goals of the PTC program was a barrier to reaching the target audience of caregiver class participants. Respondents believed that some class participants did not understand what the class was about when they signed up to participate. Several class participants believed that the PTC program was a jobs training program for home health aids. Another respondent explained,

> "The first class the people… had a misconception because they thought that they were coming to work. So some information got lost in the sauce there. And I don't, some people didn't realize it was six weeks at first, until we sat down and tell them, let them know, no, its six weeks."

As this respondent illustrates, there were points of miscommunication throughout dissemination. A lesson for future dissemination projects is that there is significant potential for confusion about the nature and goals of the program and attention needs to be given to clarifying the content, goals, and benefits to those recruiting class participants.

Members of the target cultural groups may be less likely to identify themselves as caregivers

There were a number of respondents who suggested that lack of identifying oneself as a caregiver could be a barrier to members of these communities recognizing the relevance of the program to their lives. Caregiving is seen as an everyday responsibility so one just does it without complaining or thinking about it as a burden. One African American class leader who conducted classes with diversity and non-diversity groups suggested that,

> "The problem we've had in the African American culture is because of the fact that you don't realize you're a caregiver. It's something you're supposed to do, you're supposed to take care of mom and dad. So when they present the information that particular way, it doesn't appeal to them."

At the same time the advertisements for a "caregiver" class often drew the interest of people interested in working in home health care. It is possible that despite recommendations from the advisory council to simplify the advertising message, more information should be provided order to communicate the purpose of the class to those who do not recognize the program as relevant to themselves or mistake it for an employment training class.

Recommendations

Recruit with word of mouth advertising but also build widespread familiarity with the program

Two main themes emerged in respondents' recommendations for disseminating the program. First, respondents suggested using strategies that were personal. While flyers in community locations and newspapers were not perceived as successful, respondents felt that

efforts to more directly connect with potential class participants may yield better results. This might include handing out flyers in addition to putting them up in buildings. One respondent suggested, "I would probably put flyers in everybody's mailboxes to let everybody know." Consistent with this theme, among recruitment strategies, respondents were most optimistic about word of mouth advertising. As one respondent explained, "But I do know people that actively took the class, they really realized how much someone else needed the class. And word of mouth, that's the best advertisement." Another respondent reflected,

> "We advertised a whole lot, we advertised in the community newspapers, we advertised on television, we advertised in the Buffalo News. We did a whole lot of advertising and it was still difficult getting people out. We went to other churches and all that and people really don't understand that you really don't have to feel this way. And I think it's just going to take word of mouth basically."

Personal connections with caregivers in the community has the potential to foster greater understanding of the PTC program, build trust between community members and program administrators, and increase buy-in from community members. Word of mouth advertising allowed individuals who had been positively impacted by the PTC program to share their enthusiasm for the program. These first-hand testimonials were believed to be a powerful source of excitement around the PTC program. Due to the one-on-one conversations inherent in word of mouth advertising, individuals who have first-hand experience with the PTC program can also help overcome the barrier of potential participants not self-identifying as caregivers. When discussing the program with potential participants, individuals familiar with the PTC program can discuss ways that the program may help individuals, even if these potential participants hadn't formerly thought of themselves as caregivers. Word of mouth advertising also helps build trust in the program and may also exert social influence that facilitates involvement. However, as many respondents noted, this personal relationship building takes a great deal of time.

The second theme in respondents' dissemination recommendations was the need to build general familiarity with the program so that it becomes a fixture in the community. To do this they recommended continuing to advertise in local newspapers, posting flyers, hosting booths at community events, and announcing the program in churches. They also suggested that partnering with established organizations already doing work in the communities may be one way to lend credibility to the PTC program and gain community members' attention. One respondent explained,

> "I think uniting our Powerful Tools with our calendar for Hispanic Heritage would be a great way of announcing we're here, we have people that could help you out…"

For the PTC program to become a fixture in the target communities it will require a long-term plan and support for engagement with the target communities. ECCC had asked some class leaders to plan to offer the class at regular intervals once or twice a year in the same location. This seems like a promising strategy.

Cultural tailoring performed and suggestions for additional cultural tailoring

With guidance from the advisory council, the master trainers and class leaders created culturally targeted advertising materials and selected targeted communication channels (e.g., local newspapers). Posters were created with photos of Native American, African American, and Hispanic families. In creating the posters for the Hispanic community, efforts were made to find the best way of translating the concept of caregiving and the other concepts into Spanish. The advisory council was consulted on what kinds of gifts to provide. Members of the advisory council advised to simplify the promotional information, including the amount of text. As mentioned previously, this may have been both beneficial, but also had the unintended consequence of not giving some people enough information. Some respondents believed that the promotional information did not adequately describe the purpose and content of the class, and suggested that this might have been a barrier to recruitment and also might have led to recruiting from outside of the intended audience –people who wanted to work in home health care, for example.

There was widespread agreement that the content and format of the class was culturally appropriate and consistent with people's cultural values. On participant said,

> "It wasn't judgmental; it didn't force other people's values on me. It was very middle of the road; anybody from any walk of life could use it- African Americans, Caucasians, Native Americans, those that are in the church, those that not in the church."

Overall, views were that the program translated well to different cultural settings; however, respondents did make a few suggestions to make it more inclusive and meaningful for their cultural groups.

Address unique stressors and ways of coping in class discussion. Respondents said that although the material that was presented was not at odds with Native American values and experiences, some important distinctively Native experiences were not part of the program. A Native American class leader might, for example, acknowledge and elicit discussion on the stressors specific to living in a small, close-knit Native community that weren't addressed by the program as well as culturally-specific ways of dealing with stress.

Use more culturally appropriate materials and examples. One class leader did think that the program would benefit from additional cultural tailoring because the examples and materials focused on representations of, and the experiences of white middle class people (e.g., a video, the script for the relaxation exercise). However, it is not clear if it would be possible to make these changes given the barriers to changing the course content imposed by PTC.

Use translated class materials. Class leaders attempting to deliver the program in Spanish reported that it was very difficult to translate course materials in the midst of facilitating:

> "…when you do it bilingual, is so, its hard… when you're translating, it's hard because you have to go from English to Spanish and a lot of the time that people say what they are coming across and we don't have time to listen to them, to hear them."

It was also noted that this could result in lower fidelity to the program goals: The general feeling was that it would be highly preferable to use the Spanish-language class materials.

Use an alternative program format

It was suggested that a six week commitment may be a barrier to participation and that it might be necessary to offer a program with a different format that could be added to a regularly scheduled event. There is a 90-minute mini version of the PTC program. For programs such as PTC that require substantial time commitment, it may be possible to reach a greater audience, overcome the barrier of the time and resource commitment needed to attend a 6-week program, and build a presence for the program in communities by initially offering this shorter version of the program.

Avoid associations between the program and government agencies

In Native American communities, ties to government should be downplayed. For Native Americans in the Erie County area, accepting government services has historically involved concessions that threaten sovereignty. Tribal governments and citizens remain wary of government services. Furthermore, value is placed on self-sufficiency. Recruiting material should emphasize local endorsement and not mention government agencies. ECCC made efforts to do this; for the Native American class, class leaders registered participants themselves instead of using Central Registration and the they did not share the same set of caregiver resources as the other classes. It was indicated that lack of trust in government agencies may be an issue in the Hispanic and African American communities as well. Agencies may want to enquire into level of trust in the agency at the outset of dissemination and adjust the extent to which they are visibly involved accordingly. Agencies should also be sensitive to mistrust when deciding whether to collect contact and other personal information from participants. It may be necessary for community representatives to do this and not share this information with the agency.

Incentives appreciated but not always necessary

To encourage participation and retention, participants in the diversity program received trinkets at each class (e.g., drawstring bag, stress ball, letter opener) as well as a meal or snack. They did not pay $25, the cost typically associated with the book required for the class. Outside of the diversity program, participants' insurance sometimes, but not always, covers the cost of the book, and light refreshments might be offered by the venue if the class is held, for example, at an assisted living facility. Class venues, typically a church or agency, received a $200 donation.

Respondents liked and appreciated the trinkets but most did not think that they were necessary for maintaining commitment to the class. They thought that, in itself, the class was valuable enough to keep attendance high.

Offering food and childcare perceived as important

Neither the African American, nor the Hispanic respondents said that food would be necessary to draw people to the class and increase attendance. They did, however, universally appreciate it and think it was a good idea, not only for increasing interest in and commitment to the class, but also to facilitate openness and participation by those attending the class. One of the class leaders observed that, "Well you know how food is; it helps people; it breaks down a lot of barriers, kinds of pulls people together." Sharing food may help create a more intimate, safe environment for participants to open up and share their experiences with one another. It also carves out time, as one person observed, for less scripted exchanges that might bring forth discussion that would otherwise not have taken place.

Native American respondents stressed the importance of offering food. Offering food acknowledges the value placed on hospitality. "We always serve food or drinks… that's traditionally what we'll do, even if somebody comes to our house." It was also suggested that consideration be given to offering childcare. It was perceived that providing childcare would help offset the burden of coming to the class. ECCC was prepared to reimburse for childcare for the Native American classes, but did not as this may not have been needed in the class that was conducted.

Finally, some respondents mentioned that having respite care available for meeting times would make the class more accessible.

Charging for the class materials would be a disincentive

Respondents did think that asking people to pay $25 for the class would be a disincentive to some and would reduce the likelihood of participating. They said that some participants would not be able to afford the cost and others may not see the value of signing up for the class. Some health insurance plans cover the cost of class participation. Future programs might utilize this strategy as a way to reduce the cost of programs for participants and funding agencies.

Reaching additional audiences

One respondent observed that recruiting had primarily taken place in low SES neighborhoods. This person suggested reaching out to the middle and upper middle class where one might find more interest in and commitment to the program.

Although many agreed that within the African American community, churches are central to community activity and recommended offering the program through the churches – one respondent recalled an example of someone who said that they would only feel comfortable attending the program in the parish – some believed that it was probably necessary to offer the program outside of the church as well. They mentioned that some people did not go to church and there can be a divide between those who do and those who do not attend church regularly. They also mentioned that it can be challenging to schedule a class at a church because of constraints on the church calendar and space limitations. Offering the class may also be a financial burden on the church, dampening support from pastors. ECCC attempted to reduce this burden by offering a $200 donation to venues where classes were held.

Table 6. Engaging Class Participants Major Themes and Implications for Dissemination

Major themes
1) The diversity program had been advertised in newspapers, on the Erie County Senior Services website, in church bulletins, posters in a limited number of locations, included among information provided at community events (e.g., health fairs), and announcements made in churches. While respondents felt that their communities had low to no awareness of the program despite these efforts, they perceived that with continued effort and time, awareness would increase. 2) Respondents identified word of mouth advertising as the most labor-intensive, but the most likely to result in someone taking the class. 3) Class leaders may be confused about the purpose of the program, resulting in failure to recruit the target audience (e.g., recruiting people interested in becoming home health aids). 4) Members of the target racial/ethnic groups may not identify themselves are "caregivers", which could be a barrier to recognizing the relevance of the program to their lives. 5) Respondents felt that the class curriculum was culturally appropriate for their communities. Most felt that adaptations such as including content on culturally-specific stressors and ways of coping, or adjusting for lower literacy could be made while using existing class material. 6) Using English materials to lead a class in Spanish was perceived as very challenging. 7) A six-week, 15-hour commitment may be a significant barrier to participation. 8) Respondents believed that offering food at the classes was an incentive to participation and helped facilitate trust and communication between participants. 9) Trinkets were appreciated, but not perceived as necessary by most. 10) Most thought that charging for the class would be a disincentive to participation.

Engaging Participants Implications for dissemination

1) The primary agency may need to request funds to enable them to establish a network of individuals who identify potential participants. For example, the agency might approach primary care providers and seniors centers to identify potential participants and recommend the program.

2) Consider initially offering abbreviated versions of the program to build interest in the program and reduce the need for time-intensive commitment by participants and class leaders alike.

3) Use translated materials.

4) The concept of "caregiver" may not resonate with the target communities. An iterative process of developing and testing promotional materials may be required to create effective advertising concepts and materials.

5) If budgetary constraints are a barrier to offering incentives, priority should be placed on offering food and reducing the cost of the course for participants. It might be possible to offer the class at reduced cost for those who cannot afford it by making class fees "by donation".

Conclusions

The approaches used by the ECCC to disseminate the program were consistent with those described in the literature as helpful for increasing program accessibility[7] or engaging communities:[8,9] involving local community leaders and organizations in raising awareness about the program; advertising in ethnic-specific media; reducing barriers to participation such as cost and offering the program in convenient and familiar locations; offering the program in participants' first language; culturally tailoring promotional materials; culturally matching personnel (i.e., class leaders) and participants; involving community representatives in an advisory capacity; and building a trusted presence in the community through participation in community events.

Perhaps the most significant challenge faced by ECCC was not having adequate resources to use each of the aforementioned strategies intensively enough. Similar future projects might plan for ways to maintain frequent communication with advisory board members, community organizations that might host or promote the program, and community leaders who might endorse the program in order to inform them in detail about the purpose and format of the program, dissemination progress, and close follow-up regarding commitments from and to these individuals. Future projects might also plan for frequent participation in community events that demonstrate tangible commitment to the community. It would be helpful, for example, to have a paid staff person whose chief responsibility is relationship building with community members, recruiting class leaders, and organizing and promoting the classes. Intensive follow-up with community partners and trust building through community engagement may be necessary and beyond what can be accomplished by staff that is already committed to existing programs. This also offers an opportunity to hire an individual with existing ties to one or more target communities.[10]

A future project might also focus on a single community as a means of intensifying outreach activities. Engaging more than one community at a time may spread resources too thin. Intensifying community outreach is especially important for agencies that are without established relationships and a history of engagement in a target community. Significant resources and time will need to be devoted to these activities unless the agency already has them in place. Furthermore, agencies, in particular, government-affiliated agencies who wish to engage with the Native American communities in Western and Central New York will need to devote considerable time and resources to relationship building in order to overcome a legacy of infringement on sovereignty and institutional racism by American governments.

ECCC used an impressive number of engagement strategies; however, to supplement these, future projects might consider additional ways to reduce barriers to participation. One such barrier was the commitment required of participants, class leaders, and hosting community organizations in order to run a 6-week program. One strategy would be to initially offer a shorter program that requires less commitment from participants, class leaders, and venues alike, to build presence and trust in the community before introducing a lengthier program. For example, future efforts to disseminate PTC might involve offering the shorter, 90 min PTC program and only introducing the full 6-week version after the community has shown significant interest in and commitment to the program. A second

barrier is the challenge of inspiring commitment in community partners, advisory council members and class leaders. Frequent communication should be helpful; however, to is has increasingly been recognized that it is important to compensate community members for their time.[10] Future projects should compensate community participants such as advisory board members and others playing significant roles as the class leaders do in the PTC program. When community members are paid, it may be possible to ask them to participate in program dissemination in more concrete and time-intensive ways (e.g., speaking about the program at community events).

Informal interpersonal communication seems to be more effective at raising awareness and participation than traditional advertising. A number of programs targeted at African American and Hispanic audiences have shown benefit from using a narrative approach to engage and persuade participants where community members provide testimonials that promote and increase trust in the program.[11,12] Given that participants and class leaders who have participated in the program have such positive feelings about the program, this might be a powerful way of recruiting new participants.

Evidence indicates that modifying the form and content of psycho-educational programs to reflect the experiences, values, and beliefs of the target audience improves uptake and effectiveness.[13] However, users of the PTC program and other evidence-based programs may not be able to make substantive changes to program curriculum and delivery format. Fortunately, most participants did not see a pressing need for the program to be adapted for their cultural group. The desire for group discussion about culturally specific stressors and ways of coping can certainly be accommodated because of the ample time allowed within the program for participants and class leaders to talk about their personal experiences.

Will ECCC be able to sustain a more diverse PTC program now that the funding period for the diversity program is complete? Having trained 19 minority class leaders should increase the likelihood of holding classes in these communities. Hopefully holding classes in minority neighborhoods will continue to be a priority for ECCC, and special attention will be paid to encouraging and supporting the minority class leaders. Also, it will be important for ECCC to continue to build relationships with these communities by attending their events and networking with community leaders. The outlook for sustainability in the African American community may be the most positive. A major hospital system, situated in a predominantly African American neighborhood, has agreed to host PTC class on a regular basis. Also, Time Warner will host twelve half-hour segments about PTC and caregiving on its local access channel (Channel 20) during a one year period. These television shows will be produced and hosted by an African American class leader and will feature interviews with the master trainers, and brief sections of the PTC class content. The approach seems promising and perhaps might be translated to a format that could be used for in-person outreach in the Hispanic and Native American communities.

Conclusions: Summary

ECCC faced significant challenges in disseminating PTC to the African American, Hispanic, and Native American communities in Erie County and the surrounding area. The challenges did not appear to be due to poor reception of the program. Despite not being culturally tailored, the program was well received by participants. In contrast, the challenges appeared to primarily be attributable to the difficulty of creating relationships that would be a basis for recruiting class leaders and organizing classes in communities in which there had

been very little previous ECCC presence and no familiarity with the PTC program. Considerable time and resources are needed to build a trusted presence in a community and create ties with both formal and informal community leaders. Without existing relationships on which to piggy back, it can be anticipated that a lengthy and active commitment to a community will be necessary before awareness of and perceived need for a program are solidified.

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