Using Community-based Participatory Research to Target Health Disparities

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Abstract

Community-based participatory research (CBPR) is an action research approach that emphasizes collaborative partnerships between community members, community organizations, mental health and biomedical providers, and researchers who are directly affected by an issue in order to generate knowledge and solve local problems. Although relatively new to the field of family social science, family and health researchers have been using CBPR for over a decade. This paper will introduce CBPR methods, illustrate the usefulness of CBPR methods in families and health research, describe two CBPR projects related to diabetes, and conclude with lessons learned and strengths and weaknesses of CBPR.

Community-based participatory research (CBPR) is an action research approach that emphasizes collaborative partnerships between community members, community organizations, mental health and biomedical providers, and researchers who are directly affected by an issue in order to generate knowledge and solve local problems (Mendenhall & Doherty, 2005; Minkler & Wallerstein, 2003; Israel, Eng, Schulz, & Parker, 2005). Hierarchical differences that typically arise between providers and patients are flattened through this partnership and all participants work together to co-create knowledge and effect change throughout all aspects of the research process (Lewin, 1946; Doherty & Mendenhall, 2006; Mendenhall & Doherty, 2005). Each partner contributes unique strengths and knowledge to improve the health and well-being of community members (Minkler & Wallerstein, 2003; Israel et al., 2005). Because CBPR focuses on a problem within a specific site or community, the "local" problem is addressed directly and in-context (Hambridge, 2000).

While still not widely practiced in family science circles, CBPR has gained increased credibility in healthcare (e.g., medicine, nursing) and public health since the early 1990s because of its potential to inform understanding of individuals' experiences and improve or generate services provided to them (Heslop, Elsom, & Parker, 2000; Kovacs, 2000). CBPR has been employed in a wide range of areas, including hospice access and use by African Americans, impoverished Hmong women dealing with depression, health audits, smoking cessation, primary care and diabetes management, dental and mouth-care practices, management of preoperative fasting, patient problem-solving skills, patient and practitioner satisfaction, patient-practitioner communication, and a number of other significant healthcare issues (de Amorim & Cavalcante, 1992; Hampshire, Blair, Crown, Avery, & Williams, 1999; Lindsey & McGuinness, 1998;

McGarvey, 1993; McKibbin & Castle, 1996; Mendenhall, Whipple, Harper, & Hass, in-press; Reese et al., 1999; Yoshihama & Carr, 2002).

Several key assumptions permeate CBPR projects (Israel, et al., 2005; Mendenhall & Doherty, 2005; Minkler & Wallerstein, 2003) including: 1) CBPR acknowledges the community as a unit of identity in which all partners have membership in. 2) CBPR emphasizes democratic partnerships between all project members (e.g., clinical researchers, community participants) as collaborators through every stage of knowledge- and intervention-development. 3) CBPR requires a deep investment in change that carries with it an element of challenging the status quo, improving the lives of members in a community or practice, and attending to social inequalities. 4) CBPR builds on strengths and resources within the community in order to address local concerns and solve relevant problems. 5) CBPR uses a cyclical process in which a problem is identified, solutions are developed within the context of the community's existing resources, interventions are implemented, outcomes are evaluated, and interventions are modified in accord with new information as necessary. 6) CBPR promotes project partners' humility and flexibility to accommodate changes as necessary across any part of a project and fosters co-learning and capacity building. 7) CBPR involves a long-term process and commitment to sustainability. For a further review of CBPR see Minkler & Wallerstein, (2003) and Mendenhall & Doherty, 2005.

Due to the spreading interest in CBPR, authors have written about CBPR research conceptually and identified differing levels of involvement in which community members' can participate. Arcury, Austin, Quandt, and Saavedra (1999) identify that there is broad range of what is considered CBPR, in that different members of a given community may take on varied roles in CBPR activities. "The range is characterized as active to passive, contractual to collegiate, and tokenism to degrees of citizen power" (pg.564). They also emphasize that citizen

power is the most effective type of active participation by community members, but is least likely achieved. Thinking of CBPR participation as a continuum is realistic and all types of CBPR are beneficial, but our research corroborates the opinion that having community members involved at the highest level of collaboration, or utilizing "citizen power," is the most effective and yields successful outcomes—even though at the front end it can often be more work.

CBPR and Family Science Research

Although relatively new to family science research, community-based approaches can be linked to early family life education (FLE) outreach efforts. Early roots connecting family life educators to community-based approaches include: collaboration between church and state in the early 1800's to ensure that children were raised according to biblical standards, child and mother community study groups (a type of support group) in the early 1900's that became the Parent Teacher Association (PTA), and the growth of community-based parenting education programs in the 1920's that evolved into the National Extension Parent Education Model in the late 1990's (Duncan & Goddard, 2005; Lewis-Rowley, Brasher, Moss, Duncan & Stiles, 1993). More recently, CBPR has been used in family and health research by several family researchers (Doherty, Mendenhall & Berge, 2008; Garwick & Auger, 2003; Mendenhall & Berge, in press; Piercy & Thomas, 1998). In alignment with family systems thinking, which emphasizes the importance of relationships embedded in and across all aspects of family life (rather than focusing on the individual or community in exclusion of the family), CBPR methods have the potential to effect change on many system levels related to research, prevention, intervention and education in the field of family science.

CBPR and Families and Health Research

Community-based participatory research (CBPR) in families and health research is becoming more common due to its usefulness in activating patient and families around the management of chronic conditions. Many chronic conditions have been resistant to traditional models of research inquiry due to the fact that traditional health care research typically aims to deliver health care "to" patients– rather than working "with" patients and family members to increase ownership of the problem. For instance, CBPR is especially useful with families with members with chronic health conditions because family members, especially parents, typically struggle with how to help their family member without being overbearing or too protective (Berge & Patterson, 2004; Berge & Holm, 2007). CBPR allows the family members to work together to find solutions in collaboration with professionals. CBPR also allows for larger system involvement such as family and community entities that often get overlooked in traditional investigator driven research due to the cost, effort and difficulty with measurement issues. Due to the highly collaborative nature of the method, the more people involved equates to more potential solutions and support for the implementation of the solutions. Although, to our knowledge, there have been no clinical trials comparing CBPR approaches to traditional investigator driven designs, CBPR approaches have been found to be effective with chronic conditions in which provider and patient frustration is high, such as diabetes, asthma, chronic pain, and depression (Davis, Clay, Smyth, Gittelsohn, Arviso, Flint-Wagner, Rock, Brice, Metcalfe, Stewart, Vu, & Stone, 2003; Garwick & Riesgraf, 2007; Mendenhall, Berge & Doherty, (in press); Mendenhall, & Doherty, 2007).

The two CBPR projects presented here were guided by the Citizen Health Care model (Doherty & Mendenhall, 2006; Doherty, Mendenhall, & Berge, in-press; Mendenhall, Doherty, Baird, & Berge, 2008). This model is a type of CBPR applied specifically to the health care

setting. As described elsewhere (Doherty & Carroll, 2002, 2006; Doherty & Mendenhall, 2006; Doherty, Mendenhall & Berge, (in press)), the model includes six guiding principles (see Table 1) and seven core strategies (see Table 2) for implementing citizen action initiatives. It stresses the importance of civic engagement to strengthen family life, emphasizes the need to transcend traditional provider/consumer models of health care and professional service delivery, and offers a vision of families and professionals together creating public initiatives.

   The Citizen Health Care Model. The Citizen Health Care Model is based on CBPR principles and tenets of the biopsychosocial systems model. First advanced by Engel (1977) and later extended by McDaniel, Hepworth, and Doherty (1992), the biopsychosocial systems model integrates multiple systems in the medical, behavioral health, and public health arenas, along with interactions among patients, families, and health care providers. The model highlights the importance of collaborative work between professionals trained in a variety of disciplines, and utilizes treatments that attend to the complex, holistic nature of patients' and families experiences. This is particularly important in terms of studying family- and community-based interventions with health disparities, because multidisciplinary teams of providers tend to be the norm, and CBPR methods encompass complex systemic interactions between patients, patients' families, providers, and multiple influences within their communities.

   As outlined in Table 1, Citizen Health Care begins with the notion that all personal health problems can also be seen as public problems (e.g., How does widespread diabetes affect an ethnic community's sense of dignity and social pride? In what ways is depression breaking down families in a community?). In addition, Citizen Health Care moves interdisciplinary collaboration from treating one patient at a time to collaborating with families and communities to effect change on a larger scale. The model is a systematic way to access a resource that is

largely untapped in our contemporary health care system(s): the knowledge, lived-experience, wisdom, and energy of individuals and their families who face challenging health care issues in their everyday lives. The notion of "citizen" refers to individual and their families becoming activated along with their neighbors and others who face similar health challenges in order to make a difference for a community. Ordinary citizens become assets in heath care as they work as co-producers of health for themselves and their communities.

Table 2 outlines the main strategies for implementing the Citizen Health Care CBPR approach and "first steps" suggestions for initiating a project and community partnerships. These strategies and first steps have worked successfully for our research team as we have engaged a variety of communities in Citizen Health Care, tackling several important health care problems. The "ANGELS" project below will specifically highlight the "development process" of CBPR.

Research Components of the CBPR Process

One important element that is pervasive throughout the CBPR process is the aspect of "research". Establishing statistical significance of CBPR projects is essential, otherwise the projects potentially could be misinterpreted to be program development projects only. Thus, a main focus of each project is to establish research elements from the beginning. The CBPR projects described below collected both qualitative and quantitative data, agreed upon collaboratively by community members and researchers. Early on in the process the groups identified important research questions to investigate, including both community members' and researchers' agendas. In most cases the questions overlapped, or were easily combined to meet the needs of all collaborators. As data were analyzed, findings were regularly presented back to the group, who gave feedback regarding the accuracy, usefulness, and implications of the findings. The immediate relevancy of these data were ascertained in this process by the group,

and data were acted upon (or not) according to this collaborative, self-sensitive feedback process.

Publications/presentations. Disseminating the research is another important aspect of CBPR. This allows for important findings to be distributed to both academic researchers and the families/community involved in the research. Results communicate success of the project, the changes brought about by the project, and the efforts of the researchers/families/community to sustain the project. In the above projects, researchers and community members have done several presentations together. At the same time, community members and researchers have done presentations and/or publications on their own. Each time a presentation or publication is submitted, a conversation ensues regarding who should be involved and in what capacity.

Pilot data to randomized control trial (RCT). Similar to any new intervention study, CBPR projects begin as pilot studies that are honed and developed into randomized control trials. This is an important transition step, which brings credibility to the CBPR project. All of the projects mentioned below are in one of three stages: development (ANGELS), gathering pilot data (FEDS), or transitioning to an RCT (FEDS is now acquiring funding for an RCT). The "FEDS" project below will emphasize the "research process" of CBPR.

A Neighbor Giving Encouragement, Love and Support (ANGELS)

Purpose. To improve the well-being of families who have adolescents living with diabetes.

Background. Type 1 diabetes is the third most common chronic illness in youth, and Type 2 diabetes (once thought to occur almost exclusively in adults) is consistently correlated with pandemic increases in childhood and adolescent obesity and physical inactivity (Fagot-Campagna, Burrows, & Williamson, 1999; Hampson, Foxcroft, Skinner, Kimber, Hart, Cradock, Storey, McEvilly, & Gage, 2004). Adolescents as a group maintain the worst glycemic control when compared to any other age group (Gage, Hampson, Skinner, Hart, Storey, Foxcroft,

Kimber, Cradock, McEvilly, 2004). This represents a significant health concern, because poor diabetes management during adolescence is strongly associated with the onset and progression of a variety of short- and long-term physical and mental health complications in adulthood (Couper, Fotheringham, Taylor, & Sawyer, 1999; Hampson, Skinner, Hart, Storey, Gage, Foxcroft, Kimber, Shaw, & Walker, 2001).

   CBPR process. Providers in the Pediatric Department of a large academic hospital had been frustrated for a long time with diabetes self-management with their adolescent patients. While some teens adhered to prescribed regimens of physical activity, diet, blood sugar monitoring, and insulin administration, a large proportion of patients were managing their disease quite poorly. Repeated efforts across conventional interventions were not working – from teaching community classes about diabetes and self-care, to hosting diabetes-related fairs and public forums, to the consistent provision of warnings during standard care visits about a variety of long-term consequences associated with poor metabolic control. Adolescent patients continued to evidence unhealthy physiological indicators (e.g., hemoglobin A1c and body mass index) and little apparent motivation to change. Parents complained about being "nags" to teenagers who wanted to be left alone. Adolescents complained about adults (parents, providers) who would not "get off their backs" or allow them to have the same freedom and spontaneity as their peers. Providers felt triangulated into family conflicts – oftentimes right in the exam room – without any clear idea about what to do other than go over the same old information and cautionary warnings.

   Initial conversations between the director of Pediatrics and University researcher (Tai Mendenhall) ensued to identify new ideas for this old and increasing problem. The researcher suggested that a community-based participatory research approach be applied to this problem because it would move efforts beyond the conventional top-down services these adolescents and

their families were resisting. The director had strong buy-in because he had seen numerous traditional attempts fail, but was optimistic that there was still an unknown solution yet to be found (action strategy #1; see table 2). Not being familiar with flat-hierarchy interventions involving active patient and family participation in partnership with providers, but maintaining an investment to address the problem with an openness to try new solutions, the director mobilized other providers to meet (action strategy #2; see table 2) , learn about CBPR, and decide whether and how to proceed (action strategy #3; see table 2).

Early meetings between researchers and providers addressed how to engage patients as collaborators in the design of supplemental services to standard care (action strategy #4; see table 2). This would tap a variety of resources previously untapped, including patients' and families' lived experience and wisdom of living with diabetes on a day-to-day basis. The Citizen Health Care Model was introduced as a guiding framework for this work. Through the lens of this model, it was explained that providers are viewed as citizens with knowledge and skills who work actively with other citizens who also possess important knowledge and skills. Also, how participants in this work self-consciously and explicitly avoid conventional provider/consumer dynamics by recognizing and valuing all members' respective contributions to a common mission. Furthermore, that families are active producers and co-creators of action and change, and thus do not function in a conventional consumer/patient role.

Six families, through their providers, were then invited to meet with providers and researchers to discuss ideas regarding the building of a citizen initiative that would benefit families struggling with diabetes (action strategy #5; see table 2). The stage was set to work collaboratively, and a great deal of attention was spent discussing and understanding how these efforts would not follow the conventional top-down sequences of a provider-led approach.

Adolescents and parents were enthusiastic about creating something new through CBPR, with the larger vision of developing a model of care by and for its citizens with all participants functioning as stakeholders in the process. Adolescents, in particular, were very active in the process because they felt listened to and valued. The group collaboratively identified key areas of concern, and developed solutions within the contexts of the hospital and surrounding community's resources. As adolescents, parents, providers and researchers met over the following 6 months as the action planning group, an exciting new program was named by the group and began to take root (action strategy #6; see table 2).

Through the ANGELS (A Neighbor Giving Encouragement, Love, and Support) adolescents and their parents who have lived experience with diabetes (called "support partners") were connected with other families (called "members") who were struggling with the illness. These efforts begin at the time of diagnosis, which occurs almost universally in the context of emergency hospitalization. It is during this time that the initiative's teens maintained that they wanted the ANGELS to connect with members, because the motivation to adopt healthy lifestyles is the highest at a time of crisis. Support partners and members met at the time of hospitalization in a variety of combinations (e.g., adolescents with adolescents, parents with parents, families with families), and then continued to meet off hospital grounds (or via telephone, e-mail, internet discussion boards) after initial hospitalization. Sometimes members simply needed a pep talk; other times ongoing support was offered for several months.

Adolescents and parents in the ANGELS program worked democratically with providers and researchers throughout every stage of its development – from initial brainstorming regarding the program's mission, naming process, training design, public-visibility efforts, implementation, and ongoing problem-solving and maintenance (action strategy #7; see table 2).

Research process. This project is still in the development phase and the action planning group has been meeting ongoing to determine outcomes for a pilot project. For instance, they have identified outcomes such as: changes in metabolic control (A1c) and family functioning between groups receiving support through the ANGELS program in addition to standard care versus those receiving standard care exclusively (action strategy #7; see table 2). Antidotal accounts suggest that the program's usefulness will be further validated as these evaluative efforts are advanced.

Results and next steps. Intentionally relying on existing community resources, the ANGELS program has maintained its democratic character and ensured its long-term viability as a resource within its community. Initial efforts are now in process regarding the training of a new generation of support partners – many of whom were members at one time that were connected with this program during their own crisis and early struggles with diabetes. Support partners' sense of personal ownership in the ANGELS continues to be reflected in this progression as they are assuming responsibility for components of this training and long-term vision.

Department of Indian Work/Family Education Diabetes Series ("FEDS")

Purpose. To improve the health of American Indian (AI) families and their family members who live with diabetes.

Background. Diabetes is one of the most widespread chronic diseases in this country, with current prevalence estimates exceeding 6% of the general population (ADA, 2005) The AI population is the hardest hit, with prevalence rates as high as 50% among certain tribes (Naylor, Schraer, Mayer, Lanier, Treat, and Murphy, 2003). Secondary prevention is also a critical concern, as AIs experience higher rates of diabetes-related complications – comorbid heart

disease, reduced or lost vision, amputations, and kidney disease – compared to Caucasian and other racial/ethnic groups (Parker, Haldane, Keltner, Strickland, & Tom-Orme, 2002).

AI community leaders and tribal elders in the Minneapolis / St. Paul area were worried about the ever-increasing prevalence of diabetes and its impact on families in the AI community. Intergenerational transmission of diabetes is common within AI tribes and many family members within the same generation frequently are living with diabetes. The pervasiveness of diabetes has been made even more alarming by the sense of defeat that many AI families communicate— that diabetes is expected and not preventable. Providers working with members of the AI community shared these concerns, and were frustrated with the failure of conventional care to address these issues. They desired to address this "family problem" as a community and to find ways for families to feel empowered over the illness, rather than disempowered.

CBPR process. University of Minnesota (UMN) researchers (Tai Mendenahll, Jerica Berge, and Pete Harper), already situated within a health care clinic, and leaders in the St. Paul Department of Indian Work (Nan LittleWalker, Betty GreenCrow, Sheila WhiteEagle, and Steve BrownOwl), already patients at the same clinic, had several informal conversations about the diabetes problem in AI families and the wider AI community. As they talked about the concerns regarding the sense of defeat, the researchers and community members decided to approach this challenge with a community-based participatory research paradigm, using Citizen Health Care as a guide. AI families in the community who were patients at the clinic were invited to participate in the action planning group. This was done by providers in the clinic nominating families who were managing diabetes well (not perfectly). During the first six months of meeting together as an action planning group, considerable effort was spent in designing a partnership with providers that was very different than conventional top-down models of care. AI family community

members succeeded in sensitizing clinical researchers regarding the process, pace, and importance of building trust within AI circles. As the team engaged in the ongoing meetings, discussions, and AI community events, this trust evolved. Researchers learned about AI culture, the diversity of cultures/tribes within this larger frame (e.g., Dakota, Ojibwe, Hocak), the importance of family, cultural belief systems, and manners. In turn, AI family community members gained more insight regarding how Western medicine is oriented, and thereby gained insight into providers' habitudes and perspectives in health care delivery.

After 6 months of the action planning group meeting, doing stakeholder interviews and creating an intervention, the Department of Indian Work's (DIW) Family Education & Diabetes Series was implemented by community AI families, providers and researchers as a supplement to standard care for families within the AI community who are touched by diabetes. Families (spouses, parents, children), the family member(s) with diabetes, and providers (physicians, nurses, dieticians, mental health personnel) come together every other week for an evening of fellowship, education, and support. Generally 6-7 providers, 4-5 tribal elders, and 12 families (approximately 35-40 community members) attend. Meetings begin with all participants checking and recording each other's blood sugars, weight, body mass index, and conducting foot checks. Families cook meals together that are consistent with AI culture and traditions, and a great deal of discussion is put forth regarding the meal's ingredients, portion sizes, and relevance to diabetes. Educational sequences follow, and take place in talking circles and across a variety of lively activities (e.g., traditional and modern music, chair dancing and aerobics, impromptu theater/role-plays). Instructional topics are similarly diverse, e.g., basic diabetes education, obesity, foot care, stress management, exercise, family relationships, retinopathy, dental care, and resources for medical services and supplies. FEDS evenings conclude with time for informal

sharing and support. These bi-weekly series are scheduled to last for three hours, but most families arrive early and stay late.

   Research process. At the beginning of the CBPR process (approximately 3 months into the process), the action planning group discussed the research elements of the project. It was determined early on that hemoglobin A1c levels, weight, blood pressure, knowledge of diabetes and psychosocial stress would be measured. These outcomes were identified by determining which issues each member of the action planning group was most worried about for AI families who were dealing with diabetes. As the issues were discussed a list was created and variables that could potentially measure these concerns were identified (e.g., concern = heart attack as complication of diabetes, variable to measure = blood pressure, weight & A1c; concern = family stress, variable to measure = psychosocial stress). During this CBPR process one stakeholder's perspective was not given advantage over another's thus, outcome variables were not included unless all parties agreed. All assessment measures being utilized in the study were also examined by the action planning group and approved. One example of the importance of using this CBPR process was made overt when the psychosocial assessment instrument was being discussed. The AI family community members identified that there was very sensitive material regarding sexual intimacy on the instrument. The providers and researchers were told that this would not be respectful to AI culture and that families may become suspicious of the research, or may not even participate, if the entire instrument was used. The action planning group decided to remove the subscale that involved sensitive material and use the rest of the instrument. This decision was beneficial because it did not alter the research question(s) being answered, but did increase the likelihood of participation.

Data collection was also collaboratively done. The action planning group decided that AI family community members would be more trusting of data collection if other AI families were involved in the collection process. The action planning group also wanted to promote diabetes self-management skills and by having AI family members collect each other's data they would be learning how to improve their diabetes self-management skills. Thus, AI family members collected data that was appropriate to collect (weight & BMI, foot checks, exercise logs, blood sugars) and the providers and researchers collected data that was specialist-specific (paper assessments, A1c levels and blood pressure). AI family community members, providers and researchers were all present at the FEDS meetings in order to promote the idea of a partnership and co-creation of health.

As analyses were run by the researchers, the action planning group discussed the results and next steps. Many positive changes were seen related to weight, A1c and psychosocial stress. One area that was not showing improvement, and in some cases was getting worse, was diabetes knowledge. The action planning group decided to investigate potential problems with this variable. The instrument itself was re-visited, how the information was being taught was looked at, and how the instrument was administered to the participants was examined. It was decided that how the information was being taught was not translatable into laypersons language. In the next series an AI elder taught the session about diabetes 101 and the diabetes knowledge score for participants went up, or was consistent (rather than decreasing or being inconsistent).

As the project evolved, the action planning group discussed presentations and publications. It was decided by the action planning group that each time a presentation or publication was submitted, a conversation would ensue regarding who should be involved and in what capacity. Over 15 presentations have been done to-date, in which about half are with family members of

the AI community, providers and researchers, while the other half have been done by researchers themselves, or by AI family community members. Several publications have also resulted from this work. The action planning group decided that communicating the results of the project to a broad audience was important. Thus, some of the publications are in academic peer reviewed journals, and others are in newsletters, newspapers, or reports. Authorship is determined beforehand and follows a pre-set pattern. For example, the first author must be directly connected to the venue in which the article will be published (e.g., academic journal = researcher, medical newsletter = provider, newspaper or community report = AI community family member). Grants have also been written collaboratively. The action planning group determined that the researchers would write the initial drafts of the grant. AI community family members and providers then give feedback on the draft. Final approval of the grant is given by the entire action planning group.

Results and next steps. Pilot data (n = 40) has shown significant improvements in participants' (patient with diabetes and family members) blood pressure, weight and metabolic control. Of note, participants with diabetes hemoglobin A1c levels have significantly improved, as well as, their weight (Mendenhall, Berge, & Harper, under review). The results of this pilot data are now being used to obtain funding for a randomized control trial to test this intervention against a control group.

<div align="center">Discussion</div>

The above projects represent two of 13 CBPR projects that our research team has conducted over the past nine years (half specifically related to families and health issues). Many lessons have been learned from these projects (see Table 3). Specific points related to families and health research will be addressed below. Also, we recognize there are strengths and weaknesses

to every research approach, below are a number of strengths and weaknesses inherent to CBPR. The strengths relate to the utility of CBPR in improving family and health research (broadly defined) and benefiting the lives of a community's members. The limitations serve as cautions to those engaging in this type of inquiry, as well as challenges for those wishing to advance CBPR.

Lessons Learned

First, the pull of the traditional provider/consumer model is very strong on all sides; democratic decision making requires eternal vigilance. Conducting CBPR within the medical system means having to train providers, and patients, to go against their natural inclination to reinforce provider/consumer roles. In the CBPR projects we have been involved with this is one of the most difficult paradigm shifts we have encountered. Unintentionally, providers would readily respond to all questions related to medical issues, even if the question could be better answered by a patient (e.g., what are the major reasons for patients with diabetes to be non-compliant with their medication regimen?). Likewise, patients would literally look to the providers before answering such questions because of the traditional medical model dynamics. Over time we developed a way to help reduce these difficult exchanges by emphasizing to all partners involved in the CBPR process that the expertise of the providers should be "on tap, not on top." In other words, when specific medical or mental health questions arose that required an expert's opinion it was appropriate to use their wisdom, otherwise all questions would be answered equally by all partners involved, in order to attain true collaboration.

Second, you need a champion with influence in the institution to support the CBPR process. This relates to both the medical and community entities you are partnering with. Medical systems are demanding with pulls from every direction for physician's time, energy and attention. Introducing a new way of thinking and researching into a very rigid and busy system

is almost unthinkable. Also, community systems many times are reluctant to engage in research

due to past negative experiences, or related to an unperceived need for the research. Thus,

having a physician and/or a departmental faculty member champion, as well as a community

member with a leadership role in the community involved with the CBPR project is imperative.

Our experience indicates that it is beneficial to have support from "within" and "from above".

For example: (1) in the medical system, having a physician working on the ground in the clinic

and an influential person at the departmental level of a university; (2) in the community, having a

member with a lot of zeal, and a member with a leadership role in the community.

Strengths of CBPR

Bridging Research to Practice. CBPR is carried out in the very context(s) that researchers

seek to benefit (Colghan & Casey, 2001; Piercy & Thomas, 1998). Members of the community

define their concerns, develop and implement solutions to local-level problems with local-level

resources, and take an active role in the research process. Instead of ever having to move

research into the "real world" through practice and application, CBPR is conducted in the real

world and utilizes investigation and action as inseparable facets of its overall course—what is

produced is immediately relevant (Hambridge, 2000; McKibbin & Castle, 1996; Meyer, 2000).

Utilizing existing resources. CBPR taps resources that already exist in a community, but

which have been underutilized or entirely untapped. These resources can be personal (e.g.,

leadership skills, lived-experience and wisdom) or tangible (e.g., money, services), but they are

not created through external funding. While external funding is often used to support the project,

members gain an increased sense of ownership by identifying and using participant resources in

solving the problem (Casswell, 2000; Hagey, 1997; Minkler, 2000).

Empowering families and communities in the processes of change. CBPR's forward-vision challenges the status quo, and its participants engage actively in the process. The democratic processes between professionals and community members facilitate a flat hierarchy so that all work together to generate knowledge and affect change. Participants and family members who once felt disempowered become empowered as stakeholders in the CBPR process. As all develop a sense of co-ownership in identifying problems and solving them, CBPR participants shift from an identity of passive recipients of inadequate services to active members of a team passionately invested in change (Hambridge, 2000; Piercy & Thomas, 1998).

Weaknesses of CBPR

Slow and messy processes. CBPR is marked by a series of trials and errors through the iterative processes of identifying problems and generating solutions to improve the lives of a community (Hagey, 1997; Lindsey & McGuinness, 1998). It is common for participants in CBPR initiatives to see early efforts as completely or partially unsuccessful. Often researchers must return to the drawing board in order to accomplish the initiative's shared goals. Unlike conventional research projects in which a timeline for participant recruitment, data collection, data analysis, and reporting of results can be tentatively outlined, CBPR can be entirely unpredictable. This can be frustrating to members in the CBPR process, and professional entities who are evaluating a researcher's productivity are not as likely to be sensitive to this.

In addition, external funding at the outset can be a trap because of timelines and deliverables. Until recently, major grant funders (such as the National Institutes of Health (NIH) and the National Institutes of Mental Health (NIMH)) have not been eager to fund CBPR. Because CBPR is an iterative process with the end project usually looking very different from the beginning conceptualization, funders have been reluctant to fund such projects. Our experience

indicates that it is possible to describe specific outcomes that a CBPR project will address/measure with specific deliverables, while still maintaining the importance of the iterative CBPR process as a main component of the project. We have successfully obtained over eight grants to fund CBPR projects. We have also noticed, delightedly, an increase in program announcements from NIH and other funders calling for CBPR projects.

Conventional regulatory bodies are not familiar with CBPR. Still problematic is how CBPR is perceived by universities' institutional review boards (IRBs), and how these regulatory bodies can be convinced that this type of research is acceptable in terms of participant safety and issues of confidentiality. Due to the ambiguity of what is ultimately going to result from CBPR efforts, it is difficult to meet standard notions of what informed consent requires. Also, the public nature of CBPR initiatives makes it challenging to maintain participants' confidentiality. It is difficult to maintain anonymity in research write-ups, particularly since the participants are also the co-researchers. There exist no easy answers to these questions as yet.

Future Directions

CBPR is here to stay, as evidenced by its increasing visibility in families and health research and healthcare circles. As our efforts to improve community problems and practice charge forward, so has our need to employ research strategies that permit analyses of information and the incorporation of change processes in real-time (Greenwood, 1994; Hampshire et al., 1999; Meyer, 2000). As these efforts proceed and we continue to work together to improve communities through any variety of actions, the following points are important to consider:

Increased multidisciplinary collaboration. CBPR efforts must recognize the valuable knowledge and wisdom that multiple participants bring to the table. Many CBPR projects, however, do not involve professionals from a variety of disciplines. As professionals from a

variety of fields (e.g., medicine, nursing, social work, family science, marriage and family therapy, anthropology) employ CBPR, efforts to collaborate across disciplines will not only be practical, but also sensible because they combine a discipline's strengths with those of others around the table (Mendenhall & Doherty, 2003; Small, 1995).

   Increased visibility in graduate education. CBPR has not yet received a great deal of attention in graduate research courses across family science and healthcare fields, and students' and young professionals' exposure to this type of work is limited as a consequence (McNicoll, 1999; Small, 1995). Increasing CBPR's visibility in graduate education will better prepare our next generation of researchers and practitioners to engage in investigatory efforts that are designed to immediately benefit the communities where they live. A challenge to this call rests in the likelihood that many of the professionals who are teaching graduate research are not, themselves, familiar with this approach. Current educators therefore maintain the responsibility to learn about CBPR so they can facilitate students' exposure and interest in this type of work.

   Increased visibility in professional arenas. We must also continue to increase CBPR's visibility on a larger scale across professional arenas. This may take the form of publication in mainstream refereed journals, or increased attention in national and international forums through public presentations, posters, or discussion groups. All such efforts that facilitate widespread familiarity and exposure to CBPR will serve to augment and stabilize its position as an accepted research practice in family science and healthcare science. Its potential will only be realized when CBPR becomes an increasingly common way of working with families and communities. See table 4 for several exemplar CBPR projects done in a variety of professional fields.

   Increased acceptance by grant funders. As mentioned earlier, major grant funders have been reluctant to fund CBPR projects. Recent changes, such as program announcements from

NIH and other funders calling for CBPR projects, indicate promise for such research. CBPR researchers should continue to present and publish their findings in order to bring more visibility to this methodology. As funders continue to see the positive outcomes from CBPR projects they will continue to offer grant funding for these projects. Likewise, as more researchers are funded for CBPR projects the amount of grant money available will increase.

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Table 1: Core Principles of the Citizen Health Care Model

Core Principle	Rationale
1. The greatest untapped resource for improving health care is the knowledge, wisdom, and energy of individuals, families, and communities who face challenging health issues in their everyday lives.	Instead of first looking to professional resources, we look to family and community resources.
2. Families and communities are producers of health and health care, not just clients or consumers.	This empowers families and communities to co-create health interventions, understandings, and influence in partnership with professionals.
3. Health professionals are citizens, not just providers.	In this work, health professionals develop public skills as citizen professionals so that they can work in community groups with flattened hierarchies.
4. Citizens drive programs, rather than programs servicing citizens.	If you begin with an established program, you will not end up with an initiative that is "owned and operated" by citizens. But a citizen initiative might create or adopt a program as one of its activities.
5. Local communities must retrieve their own historical, cultural, and religious traditions of health and healing.	Each initiative should reflect the local culture in which it is positioned in order for the initiate to be co-owned; no two initiatives will look exactly alike.
6. Citizen health initiatives should have a bold vision while working pragmatically on focused, specific projects.	Think big, act practically, and let your light shine in order to sustain motivation.

Table 3: Lessons Learned from Citizen Health Care CBPR Research

- This work is about identity transformation as a citizen professional, not just about learning a new set of skills.
- This work is about identifying and developing leaders in the community more than about a specific issue or action.
- This work is about sustained initiatives, not one-time events.
- Citizen initiatives are often slow and messy during in the gestation period.
- You need a champion with influence in the institution.
- Until grounded in an institution's culture and practices, these initiatives are quite vulnerable to shifts in the organizational context.
- A professional who is putting too much time into a project is over-functioning and not using the model. We have found the average time commitment to be on the order of 6-8 hours per month, but over a number of years.
- External funding at the outset can be a trap because of timelines and deliverables, but funding can be useful for capacity building to learn the model, and for expanding the scope of citizen projects once they are developed.
- The pull of the traditional provider/consumer model is very strong on all sides; democratic decision making requires eternal vigilance.
- You cannot learn this approach without mentoring, and it takes two years to get good at it.

Table 2: Action Strategies for Citizen Health Care

Action Strategy	Rationale
1. Get buy-in from key professional leaders & administrators.	These are the gatekeepers who must support the initiation of a project based on its potential to meet one of the goals of the health care setting. However, it is best to request little or no budget, beyond a small amount of staff time, in order to allow the project enough incubation time before being expected to justify its outcomes. **First Steps:** Talk with clinic managers, department heads, & other major community organizations about the identified problem—offer to do a presentation for their staff or clinic. Get their buy-in before moving forward.
2. Identify a health issue that is of great concern to both professionals and members of a specific community (e.g., clinic, neighborhood, cultural group in a geographical location).	The issue must be one that a community of citizens actually cares about—not just something we think they should care about. Additionally, professionals must care about the issue and have enough passion for it to sustain their efforts over time. It must be a "pressure point". **First Steps:** Contact people you have connections with first. Our team networked within the health care system we worked in by talking with other doctors, administrators, patients, etc. Patients always know other people in the community with similar concerns & can help network for you.
3. Identify potential community leaders who have personal experience with the health issue & who have relationships with the professional team.	Leaders should be ordinary members of the community who in some way have mastered the selected health issue in their own lives & have a desire to give back to their community. "Positional" leaders who head community agencies are generally not the best group to engage at this stage—they bring institutional priorities & constraints. **First Steps:** One invitational strategy we have used is to have providers nominate patients & family members who have lived expertise with a health issue & who appear to have leadership potential.
4. Invite a small group of community leaders (three or four people) to meet several times with the professional team to explore the issue & see if there is a consensus to proceed with a larger community project.	These preliminary discussions help determine whether a Citizen Health Care project is feasible & begin creating a professional/citizen leadership group. **First Steps:** Employ flat hierarchies from the beginning. During meetings the facilitator does not "lead," or set the agenda themselves, rather he/she moves the process along & helps the group co-create the agenda and action items.
5. Strategize how to invite a larger group of community leaders (10-15) to begin the process of generating the project.	You must have a larger group invested in the process to facilitate a larger "We" focus. **First Steps:** Give a presentation or hold a town meeting about the identified issue. If it seems to be a pressure point to a larger group of people, invite those who have an interest to work on the problem together with you.
6. Over the next six months have biweekly meetings using community organizing principles.	The following key steps are crucial, but can be slow & messy: (a) explore the community & citizen dimensions of the issue; (b) create a name & mission statement for the initiative; (c) conduct one-on-one interviews with a range of stakeholders; (d) generate potential action initiatives & process them in regards to the Citizen Health Care model & existing community resources; (e) decide on a specific action initiative & implement it. **First Steps:** Read and become familiar with the Citizen Healthcare Model (Doherty, W., & Mendenhall, T. 2006). Read other exemplary examples (table 4) to get a clearer vision of how to implement these CBPR approaches in your community.
7. Employ Citizen Health Care processes through out the project.	The following steps will keep the initiative focused, strong, & increase sustainability: (a) democratic planning & decision making at every step; (b) mutual teaching & learning among community members; (c) creating ways to fold new learnings back into the community; (d) identifying & developing leaders; (e) using professional expertise selectively—"on tap," not "on top"; (f) forging a sense of larger purpose. **First Steps:** Collaborate with community members/families and researchers/professionals throughout every step. You can do this by keeping ongoing emails or blogs about the CBPR process. It is critical to keep all partners involved throughout the project.

Table 4: Exemplars of CBPR Research

Author & Project	Description of CBPR Project
Gallagher & Scott (1997); STEPS Project (Seniors and Persons with Disabilities Task Force for Environments which Promote Safety)	Project oriented to identifying and rectifying factors that contribute to injurious falls experienced by elderly and disabled persons in public places. Their efforts facilitated gathering data relevant to the most common locations of falls, environmental problems causing the falls, and demographics of fall victims. The group then hosted a symposium of community providers, engineers, city planners, and politicians to make recommendations leading to the repair of hazardous surfaces, removal of unsafe obstacles, and establishment of effective means to report hazards as they are recognized by members of the community.
Stevens & Hall (1998)	Project involving providers at a local women's health organization oriented to address risky sexual behavior in lesbian and bisexual women. Providers collaborated with lesbian and bisexual women (who served in the capacity of peer educators), and through these efforts gathered extensive data regarding sexual practices of the target community. These data informed both individualized and large-scale education related to safer sex practices.
Barrett (2001); MARG (Midwives Action Research Group)	Project highly invested in generating, implementing, and evaluating changes in healthcare practices as they relate to new mothers and midwifery practice in a local hospital community. Participants worked collaboratively to identify concerns regarding women's experiences during hospitalization and their access to informed choices. Changes in practice were made in response to these efforts.
Kondrat & Julia (1998)	Project in South India that was used to help rural communities improve systems of care and rehabilitation for children with disabilities. Rehabilitative service professionals worked in partnership with parents of disabled children to engage with disabled persons, families, community leaders, and indigenous health workers and identify specific needs and resources in local areas relevant to this problem. The group developed and implemented training and education outreach initiatives as a result of these efforts.
Garwick & Riesgraf (2007); Get a Head Start on Asthma	Partnership with parents, teachers and administrators of Head Start. Parents were involved in designing, implementing and evaluating the asthma project. Due to participants' limited access to the internet and low computer literacy, an "offline" web site on CD-ROM was constructed. The "Get a Head Start on Asthma" CD-ROM addresses common questions about asthma and asthma management identified by parents. Written and audio asthma information is available in English, Hmong and Spanish. The design, content and cultural relevance of the CD-ROM was first evaluated by expert panel of parent representatives and an expert panel of pediatric nurses who specialize in working with children with asthma and their parents.
Davis, Clay, Smyth, Gittelsohn, Arviso, Flint-Wagner, Rock, Brice, Metcalfe, Stewart, Vu, Stone (2003); Pathways	Pathways, a multisite school-based study aimed at promoting healthful eating and increasing physical activity, was a randomized field trial including 1704 America Indian 3rd to 5th grade students from 41 schools (21 intervention, 20 controls) in 7 American Indian communities.