

Chapter 14

Medical Family Therapy in Community Engagement



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“Community engagement” has been defined in a variety of ways over the years, ranging from petition and protests by disenfranchised groups against powerful others (e.g., businesses, governments) who have hurt or neglected them to purposeful partnerships advanced by lay community members and professional organizations. In health care, we have seen community engagement evolve from early efforts in peer support that do not directly involve professionals (e.g., Alcoholics Anonymous, Al-Anon) to those that are positioned within communities—but are professionally led (e.g., community-oriented primary care). Today, cutting-edge efforts in community engagement are gaining ground through community-based participatory research (CBPR); this manner of partnering communities and professionals is driven by the wisdom that everyone involved—patients, family members, community leaders, healthcare providers, administrators, etc.—has something to contribute. Collectively, this mosaic of expertise and energy is far more powerful than the sum of its parts.

Medical family therapists (MedFTs) represent an active and visible contributor to the advancement of community engagement and CBPR in healthcare. They bring an orientation comfortable with the complexities of multiple and overlapping human systems (biological, psychological, family/social, spiritual) and readily connect these dots within and across the communities of care provision (e.g., clinics, hospitals) and the patient populations that they are positioned within or oriented to (e.g., geographic

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locales, groups united through a shared disease or experience). To set the stage for our discussion of the practice of MedFT in community engagement, we begin by sharing the following story of Kadin (a MedFT) and Teresa (an American Indian elder).

Clinical Vignette

[Note: This vignette is a compilation of cases that represent MedFT in community engagement. All patients' names and/or identifying information have been changed to maintain confidentiality.]

"You have diabetes," the attending physician said. Teresa was lying on a hospital bed in the emergency department, surrounded by loved ones. She had been feeling very sick while at a powwow a couple of hours away from her home.

"No I don't," she said. "I've always been healthy."

"Yes, you do," the physician countered. "I recommend when you get home that you follow up with your primary care physician right away. There are a lot of life-style things that you are going to need to do to." He seemed like he was in a hurry.

Teresa started to cry. She knew many people in her American Indian community who had been diagnosed with diabetes. Most had lost toes, feet, or even whole limbs. Some had lost their eyesight. Many had died.

"I can't have diabetes," she said to her partner, Henry. He was holding her hand. "I've always been healthy. How did I get diabetes?"

When she came home, Teresa followed up with her primary care physician. Dr. Roth—Teresa called him "Dr. Scott"—had known her for a long time.

"I'm so sorry, Teresa. I know that this is scary for you," he said.

"Is this going to kill me?," Teresa asked.

"People can live long lives with diabetes. But it takes a fair amount of attention and care."

Scott and his diabetes nurse educator worked hard with Teresa over the next several months to control her new disease. Changes in diet and physical activity represented most of the work. Integrating blood sugar monitoring and tracking was a big deal, as well. Over time, Teresa's health improved. She lost more than 50 pounds. Her metabolic control (A1c) was good. She was feeling better.

In synchrony with this, Teresa became increasingly aware of how diabetes was impacting her community. She began to learn about how much more common the disease is with American Indian (AI) patients than as compared with other ethnic groups. She talked extensively with friends, relatives, and other AI community members about their commonplace sense of doom about it (i.e., that diabetes is an "expected" health problem that will eventually claim everyone). She was very familiar with how so many Native people did not (do not) trust Western medicine providers to care for them. Generations of colonization and historical trauma by Western institutions (healthcare, education, government) had, understandably, done that.

"Diabetes is decimating my people," she said during a peer support and mentoring program (called Partners in Diabetes) meeting at the clinic. Dr. Roth and Kadin, along with others, had helped to create the group.

“How do you think other members of your community would feel about coming here?” Kadin asked.

“Most won’t come here. They don’t feel safe. Or they don’t have insurance,” Teresa explained.

Then she got an idea. “Kadin? Dr. Scott? Would you two be willing to talk with me and my sister, who directs our local Department of Indian Work, about creating a program for Native people?”

For the next 2 years, they met. Considerable effort was spent in designing a partnership that differed from conventional top-down models of Western healthcare. Multiple community members worked to sensitize care providers (Kadin, Dr. Scott, and others) to the process(es), pace, and importance of building trust within American Indian circles. They talked about AI culture, the diversity of cultures and tribes within this larger frame (e.g., Dakota, Ojibwe), spirituality and belief systems, and Indigenous conceptualizations of health. In turn, community members gained more insight about how Western healthcare is oriented; they learned about providers’ habits, workloads and administrative expectations, and perspectives in care delivery.

Culminating from these efforts, the Family Education Diabetes Series (FEDS) was launched. Situated in a local AI community center, the program engages patients, their families (spouses, parents, children, and other relatives/friends), and providers (physicians and physician extenders, nurses, dieticians, behavioral health personnel, and other professionals) every 2 weeks for an evening of fellowship, education, and support. The group shares meals that are consistent with traditional Native diets. They learn about disease-related topics identified by the community through a variety of lively activities consistent with AI cultures (e.g., talking circles, Native games, creative arts). Health data (e.g., weight, BMI, blood pressure, random blood glucose, A1c) was also collected and tracked.

“I think that this is working,” Teresa whispered to Kadin as he sat down next to her one evening at a FEDS meeting. He had just shared with the group how their collective metabolic control had improved significantly over the previous 6 months, alongside an average weight loss of 20 pounds. Kadin and Teresa then turned to Dr. Scott and another AI elder who were beginning a copresentation about diabetes and foot care. All of the presentations were (are) done this way: one person with professional expertise and one community member with personal expertise and/or experience.

“Most of these folks don’t see a doctor for their diabetes,” Teresa said. It was not clear if she was talking to Kadin or to herself. “This is their ‘doctor,’ this is their ‘healthcare.’”

“Outside of the clinic’s walls,” Kadin said.

Teresa looked over at Kadin and then back at Dr. Scott and his copresenter. “Absolutely. And we’re all in this together.”

What Is Community-Based Participatory Research?

Contemporary efforts in integrated behavioral healthcare are making great strides to facilitate collaboration between providers representing multiple disciplines. However, we still tend to miss two things: (a) attention to the active roles that our patients and their families can play in cocreating health and (b) attention to the potential collective power of broader patient communities to advance health. Instead, most healthcare (“integrated,” “collaborative,” or otherwise) continues to frame professionals as the sources of knowledge, wisdom, and services vis-à-vis patients and families who are relatively passive. Further, most care that is provided to patients/families is delivered in a single patient/family at a timely manner, with no ways of connecting patients with each other along the way. Instead, patients and families sit straightforward in waiting rooms, reading outdated magazines and not talking with each other.

As large national and international organizations like the Agency for Healthcare Research and Quality (AHRQ), National Institutes for Health (NIH), and the World Health Organization (WHO) have called for collaborative efforts to address complex health and social problems that are ill-suited for conventional service delivery and/or research endeavors, community-based participatory research (CBPR) has become an increasingly visible way for us to partner with patient communities. Many are now working to extend these collaborative emphases of integrated behavioral healthcare to include collaboration with the patients and families we serve.

CBPR evolved from *action research* in the 1940s and has been framed in a number of ways since this time (see Figure 14.1). It is characterized by efforts in which

- Action Learning
(e.g., Pedler, 2011; Revans, 2011)
- Action Research
(e.g., Brydon-Miller, Greenwood, & Maguire, 2003; Stringer, 2013)
- Action Science
(e.g., Friedman, Razer, & Sykes, 2004; Rudolph, Taylor, & Foldy, 2005)
- Classroom Action Research
(e.g., Mettetal, 2012; Schmidt, 2002)
- Community-based Participatory Action Research
(e.g., Giachello et al., 2003; Maiter, Simich, Jacobson, & Wise, 2008)
- Community-based Research
(e.g., Minkler, 2005; Strand, Cutforth, Stoecker, Marullo, & Donohue, 2003)
- Critical Action Research
(e.g., DePoy, Hartman, & Haslett, 1999; Huzzard & Johansson, 2014)
- Industrial Action Research
(e.g., Goodnough, 2003; Richter & Koch, 2004)
- Participatory Action Development
(e.g., Lammerink, Bury, & Bolt, 1999; Okomoda & Alamu, 2002)
- Participatory Action Learning
(e.g., King, Gaffiely, & Gunton, 2001; Mayoux, 2005)
- Participatory Action Research
(e.g., Kemmis & McTaggart, 2005; McIntyre, 2007)
- Participatory Research
(e.g., Cornwall & Jewkes, 1995; Macaulay, Commanda, Freeman, & Gibson, 1999)

Figure 14.1 Alternative Terms in Professional Literature for CBPR

professional researchers partner with communities to generate new knowledge and solve local problems (AHRQ, 2004; Lewin, 1946). Several key assumptions permeate these projects; they include:

1. Partnerships between all project members (e.g., patients, families, care providers, researchers) are collaborative, equitable, and democratic through every stage of knowledge and intervention development.
2. Projects are built upon the strengths and resources that already exist within the community (i.e., not seeking new resources from elsewhere).
3. Reciprocal learning and capacity building strengthen contributions between engaged participants.
4. Deep investment in improving community members' health and well-being is recognizable by joining participants.
5. Iterative processes in which problems are co-identified, solutions are codeveloped within the context(s) of a community's existing resources, interventions are advanced, outcomes are evaluated in accord with what participants collectively see as important, and interventions are adapted and refined in response to outcome data.
6. Project members are humble and flexible in making changes to their interventions.
7. Dissemination of findings and new understandings is shared across both professional and lay audiences and arenas.
8. Recognition that CBPR can be slow and messy, particularly during early phases of a new initiative's development.
9. Participants recognize long-term engagement and commitment to the effort (Bradbury & Reason, 2003; LaVeaux & Christopher, 2009; Mendenhall, Pratt, Phelps, Baird, & Yonkin, 2014; Montoya & Kent, 2011; Scharff & Mathews, 2008; Strickland, 2006).

Citizen Health Care

Citizen Health Care (CHC) is a model that was designed purposefully in the spirit of CBPR as a framework for biomedical and behavioral healthcare professionals who engage with families in community settings (Berge, Mendenhall, & Doherty, 2009; Doherty and Mendenhall, 2006). It begins with the notion that all personal health problems can also be seen as public problems. For example, ethnic disparities in diabetes—like the ones that Teresa observed in our vignette, above—can be viewed in terms of their implications for a minority community's sense of dignity and social pride. It views providers as citizens with knowledge and skills who work actively with other citizens (patients, families) who also possess important knowledge and skills. The following represents this approach's principal tenets (for in-depth description of these tenets and key strategies for their implementation, see Doherty, Mendenhall, & Berge, 2010):

The greatest untapped resource for improving healthcare is the knowledge, wisdom, and energy of individuals, families, and communities who face chal-

lenging health issues in their everyday lives. Conventional healthcare renders patients and families as passive recipients of professionals' services. CHC works to integrate providers' expertise with the wisdom and resources of a local community. For example, Dr. Scott's and Kadin's disease-related knowledge about diabetes management (e.g., what constitutes a healthy diet; indicated ranges of blood sugar, body mass index (BMI), and blood pressure; ways to engage family members as active participators in co-owning new lifestyles related to exercise and disease management) is good on its own—but partnered with Teresa's and others' wisdom about Native foods, Indigenous games, physical activities, and traditional conceptualizations of health through Medicine Wheel models (Dapice, 2006; Garrett & Garrett, 1994) and habitudes of "walking in balance" to connect mind, body, spirit, and community well-being, this knowledge is made infinitely more engaging, personalized, and effective (Muehlenkamp, Marrone, Gray, & Brown, 2009; Robbins, Hong, Engler, & King, 2016; Rybak & Decker-Fitts, 2009).

People must be engaged as coproducers of healthcare for themselves and their communities, not just as patients or consumers of services. Alongside the passive roles of patients and families within conventional healthcare is the expectation that care's focus is on one patient at a time. After all, this is how insurance billing, electronic medical records, and healthcare training are generally framed. In CHC, patients and families take active roles in reclaiming their own health (e.g., exercising or changing their diets together vs. expecting identified patients to improve solely through prescribed medications) and the health of others in their broader community, however defined (e.g., those belonging to a particular geographic area, others who live with a similar health condition). Patients and family members think about—and care about—how those beyond their immediate circles are doing. They support each other's efforts toward collective healing and growth.

Professionals can play a catalytic role in fostering citizen initiatives when they develop their public skills as citizen professionals in groups with flattened hierarchies. At the same time that patients and families are socialized to be passive in healthcare, providers are socialized to lead. Community engagement initiatives can be challenging for providers until they develop skills related to working "with" people (not just "for" them or "on" them). These skills encompass a variety of proficiencies, including how to plan and facilitate community meetings and conversations, collaboratively problem-solve, cooperatively collect and analyze data, disseminate findings across lay and professional arenas, and engage—all the while—as a learner (not just a leader or expert).

If you begin with an established program, you will not end up with an initiative that is "owned and operated" by citizens. Although learnings and elements from CHC projects can spread to other communities, each project must be created or adapted in light of the unique challenges and resources within each community. To simply replicate (off-the-shelf) something that worked in a different community could miss some of these unique elements and thereby fail to

elicit a sense of co-ownership and investment by the patients, family members, and other community participants who are involved. Along the way, outside resources (e.g., a local food shelf that holds weekly cooking demonstrations) could be integrated into a larger whole—but only through active and collective agreement by its members.

Local communities must retrieve their own historical, cultural, and religious traditions of health and healing and bring these into dialogue with contemporary healthcare systems. Western healthcare strives to be “value neutral” and empirically driven. If providers’ efforts are not oriented to “best practices” (i.e., care strategies that are supported by objective research data), like-minded colleagues can challenge whatever is being done as less than ideal (at best) or even unsafe and irresponsible. And while there are benefits to empirical approaches (e.g., prescribing a treatment with the confidence that randomized controlled trials have shown that it works), there is also considerable richness in local communities’ health and healing traditions. Integrating both viewpoints and care models can serve to bolster confidence in any treatment. Further, it can sensitize Western providers to core belief systems that patients and families hold dear. For example, contemporary notions of “integrated behavioral healthcare” that are guided by the biopsychosocial-spiritual (BPSS) model (Engel, 1977, 1980; Wright, Watson & Bell, 1996) endeavor to integrate biomedical care with behavioral health and other social services. Indigenous conceptualizations of the Medicine Wheel have viewed health in such a manner for millennia. In the FEDS project, described above, Dr. Scott and Kadin could have advanced education about diabetes in a frame consistent with the BPSS model. Instead, in partnership with the wisdom of Teresa and other community elders, they advanced conversations about “walking in balance.” This served to connect effective disease management with respective components of the medicine wheel.

Citizen health initiatives should have a bold vision (a BHAG—a big, hairy, audacious goal) while working pragmatically on focused, specific projects. Projects advanced in CHC are purposefully ambitious in their vision and ultimate goals. In the FEDS, members are working toward eliminating (not just reducing) diabetes in the AI community. Along the way, pragmatic steps are identified, pursued, and completed (Mendenhall, Seal, GreenCrow, LittleWalker, & BrownOwl, 2012; Seal et al., 2016). These specific steps have included arranging community events and powwows oriented to health education, community 5-K walks, the authoring of diabetes-friendly cookbooks that feature Native ingredients, public listings of local farmers’ markets, and the creation of an American Indian Men’s Group that engages Native men in a variety of physical activities that are consistent with their culture (e.g., canoe building, lacrosse, sugar bushing, harvesting wild rice, fishing). The accomplishment of any and all of these smaller steps is, in itself, motivating and energizing to its participants as they, all the while, strive toward a larger vision of eradicating diabetes altogether.

Teams in Community Engagement

In contrast to other chapters in this book (wherein respective members of healthcare teams are described with specificity), teams engaged in CBPR can arguably include professional representatives from any discipline or institutional position. In partnership with them, these teams include patients, families, and other community members (elders, leaders, etc.) who are affected by any myriad of health presentations or social issues.

Community members. By definition (i.e., the “C” in CBPR), community members’ participation in health initiatives facilitates the inclusion of healthcare’s most commonly untapped resource: the knowledge, wisdom, and energy of the very patients and families that Western healthcare endeavors to engage. These include persons who live with a targeted health condition (e.g., alcoholism, diabetes), alongside their spouses, family members, friends, and other loved ones. They include Indigenous leaders and community elders (like Teresa), who oftentimes maintain key positions to educate providers about local cultures, customs, and habitudes that are essential for professional/community partnerships to work.

Biomedical healthcare providers. Providers whose primary training is focused on caring for patients’ physical health include medical technicians, nurses, nurse practitioners, family physicians and physician extenders, specialty care physicians (e.g., endocrinologists, nephrologists), and others. Respective representation of these fields in community engagement varies in accord with the focus of the health initiative (e.g., pediatricians involved in a teen-based initiative targeting adolescent health, primary care nurses involved in an adult-based initiative targeting chronic pain).

Care coordinators/community health workers/promotoras. These providers go between healthcare clinics and patients’ homes to provide care directly to patients in the environments wherein they need the most support. They provide education and social support for patients struggling with physical, behavioral, or social problems. They collaborate with healthcare providers to coordinate care for the patient both in the clinic and at home. They bridge the typical disconnect between what happens in the clinic and the home environment. They are keys to developing care plans and in supporting patients and providers to successfully carry out treatment plans for managing biomedical and/or behavioral health conditions.

Health educators. Providers whose primary training is focused on the provision of psychoeducation and/or skills-based instruction for patients (usually carried out in synchrony or coordination with biomedical treatment) include educators who specialize in nutrition and diabetes management, alcohol/drug use treatment, tobacco cessation, safe sex practices, family planning, disaster preparedness, life skills, and others. Respective representation of these fields in community engagement varies in accord with the focus of the community initiative (e.g., tobacco cessation specialists involved in a school initiative to reduce smoking, nutritionists involved in a diabetes program).

Behavioral health providers. Providers whose primary training is focused on caring for patients’ mental/behavioral health include couple/marriage and family therapists (MFTs), MedFTs, social workers, counselors, psychologists, and others.

Respective representation of these fields in CBPR can vary widely. School counselors, for example, are readily positioned to participate in school-based initiatives targeting a broad range of adolescent concerns (e.g., pregnancy prevention, smoking cessation). MedFTs are readily positioned to participate in health initiatives that partner with clinics and healthcare sites oriented to any of the primary, secondary, tertiary, and other contexts highlighted in this text.

Community professionals. CBPR can include professionals whose primary training is not specifically focused in healthcare but who are nevertheless positioned to offer a great deal to a larger mosaic of specialized wisdom. These can include persons who maintain administrative power and influence within involved organizations (e.g., school principals, business owners, church and/or religious leaders), employees of such organizations (e.g., elementary- and secondary-school teachers, coaches, youth mentors), and/or highly respected Indigenous/Native healers or consultants within select communities (e.g., curanderos, shamans).

Fundamentals of Community Engagement

A provider's knowledge and skills in community-engaged work begin with his or her professional identity and extend from there into the care and/or research-related activities that he or she ultimately advances. For MFTs and MedFTs in particular, this process is informed by the systems thinking that permeates everything that we do across clinical practice and integrated behavioral healthcare.

Identity as a Citizen Professional

A MedFT working in community engagement should carry with him/herself a professional identity as a citizen with special skills and expertise (e.g., as a therapist) who works collaboratively with colleagues and other citizens who have special skills and expertise (e.g., as a primary care provider or nurse, a community elder, a patient with a particular condition, a spouse or family member related to a patient with a particular condition). This "citizen professional" mind frame is an essential grounding from which to advance authentic community engagement.

Citizen professionals maintain content knowledge about health topics for which they have been formally trained. Extending beyond this knowledge, they are also sensitive to the complex connections between the personal and public dimensions of unique health topics. A MedFT or family medicine provider who works with patients living with diabetes, for example, is conversant with the biomechanics and treatment of the disease—alongside the connections between it and the fast food industry, costs of healthy foods versus unhealthy foods, cultural practices regarding diet and exercise, and larger social forces like insurance companies that cover diabetes

management (e.g., testing supplies, health visits) but not diabetes prevention (e.g., dietary education, access to fitness facilities).

Systems Thinking

Systems thinking is an advantage for MedFTs in community engagement by nature of the experience and comfort that they bring with working in groups (versus only one-on-one). MedFTs are skilled in connecting multiple people together who often begin conversations with different—and even conflicting—goals and agendas. They can facilitate processes whereby every person is heard and in so doing give voice to minority opinions and curb others from dominating a dialogue. These skills are essential in cocreating new ideas and solutions within families and other groups who were heretofore at an impasse. MedFTs understand how to pose questions to a group and allow the ensuing interactions to evolve dynamically. As they do this, MedFTs know how to function centrally so as to lead a conversation in a productive direction and when to be peripheral so as to not get in the way. This continuity between baseline MFT training and community engagement sets the stage for the public conversations and collective actions that are so central to CBPR.

Facilitating Public Conversations and Mobilizing Public Action

MedFTs functioning as citizen professionals must develop skills in facilitating public conversations and catalyzing collective—public—action. In the contexts of their “day jobs,” they skillfully interweave the “personal” and “public” dimensions of the issues that they and their patients face. They are sensitive to timing, as well, in bringing together other project participants (patients, families, providers, etc.) for public conversations. A MedFT working with Teresa, for example, has the skills to engage her and other patients in a discussion that connects the importance of physical activity to personal safety in relatively unsafe neighborhoods, to encourage patients to become active in their communities around issues of safety, and to create responses where patients can meet with each other and community leaders to effect change.

Competence in Mixed-Methods Approaches

When MedFTs function as citizen professionals in research roles, they must be methodologically flexible in order to best match data collection efforts with what is going on in the CBPR process (McNicoll, 1999; Mendenhall & Doherty, 2005). In order to be sensitive to the perspectives and needs of multiple participants, careful use of methods and measures that have high face validity and practical (and

immediate) utility is indicated. For this reason, community-engaged scholars often gravitate toward qualitative methods of data collection and analysis during early phases of the work. Exploring, for example, participants' personal experiences and viewpoints about a health issue can engage communities in identifying concerns that lead them to collective action. Qualitative inquiry can also serve to track inter-member and inter-group processes as interventions are democratically and collaboratively developed, as action is taken, and/or in assessing satisfaction with the results of new interventions. While objective (read: quantitative) measures of "success" can be created to assess a program's impact on a particular dependent variable (e.g., changes weight or metabolic control in FEDS participants), most projects do not do this until after a project is comparatively underway.

Consistent with this frame, a myriad of qualitative data in CBPR have been described in the literature, including in-depth interviews (Allen, Culhane-Pera, Pergament, & Call, 2010; Lindsey & McGuinness, 1998; Mendenhall & Doherty, 2003; Mendenhall et al., 2012; Razum, Gorgen, & Diesfeld, 1997), naturalistic case studies (Casswell, 2000; Holkup, Tripp-Reimer, Salois, & Weinert, 2004), reflexive journaling and meeting minutes (Hampshire, Blair, Crown, Avery, & Williams, 1999; Mosavel, Ahmed, Daniels, & Simon, 2011), focus groups (Seal et al., 2016; Small, 1995), participant observation (Lindsey & McGuinness, 1998; Maxwell, 1993; Rhodes, Malow, & Jolly, 2010), social network mapping (Bradbury & Reason, 2003; Ramanadhan et al., 2012), and oral histories and open-ended stories (Madsen, McNicol, & O'Mullan, 2015; Sieber, 2010). Access to many of these types of data is generally easy for investigators in CBPR, because the very nature of the work requires that they be active participators in the research that is being evaluated (Coughlin, Smith, & Fernandez, 2017; Israel, Eng, Schulz, & Parker, 2012).

Whereas qualitative analyses are especially useful in helping investigators to understand participants' contexts, cultures, beliefs, attitudes, community practices, and subjective experiences related to CBPR processes, quantitative measures are most usually and most usefully employed to evaluate an intervention's efficacy (Israel et al., 2012; Mendenhall & Doherty, 2005; Reese et al., 1999). These efforts are also important on "political" grounds, insofar as formally testing for objective change in tangible measures (whatever measures these may be) helps to advance confidence by the broader scientific community that the work is rigorous and credible (Minkler & Wallerstein, 2011; National Institutes of Health, 2009). For example, it was not until the authors had quantitative data confirming effectiveness in the above-referenced FEDS project that our team was able to secure ongoing external grant funding to support the work.

Consistent with basic tenets of CBPR, however, it is important to involve participants in selecting what to quantitatively evaluate, test, or measure. For example, in a CBPR initiative designed to reduce on-campus smoking, participants (researchers and community members) discussed how students' smoking prevalence was—and was not—an important measure of "success." Students saw the number of available after-school activities (delivered to target stress and boredom) as a more important quantitative measure of success than the straightforward number of students who reported that they smoke. Put simply, they saw after-school activities as a stage set-

ter for the improved self-efficacy and social support that students needed to eventually quit smoking—and they were right (Mendenhall, Harper, Stephenson, & Haas, 2011; Mendenhall, Whipple, Harper, & Haas, 2008).

In another project, providers involved in a diabetes CBPR initiative for adolescents saw metabolic control as the most important dependent variable of success, whereas adolescent patients wanted to track school policies regarding whether students with diabetes were allowed to go on fieldtrips with their peers (Mendenhall & Doherty, 2007). As the MedFT facilitator of this initiative worked to align these very different foci within the group, a collective sense of ownership in action items and outcome data evolved; school policies regarding fieldtrips were altered, and teens' disease management and physical health improved.

A project aimed at childhood obesity prevention identified increased physical activity as an important outcome, alongside increasing social capital (connectedness), as a key outcome in its neighborhood community (Berge et al., 2016). In this and other CBPR projects, what was (is) tested quantitatively is up to the whole group to decide. It is important to note, too, that these quantitative analyses tend to remain “local”—i.e., for, by, and within the community in which a project is positioned (Mendenhall & Doherty, 2005; Minkler & Wallerstein, 2011). Efforts to test widespread generalizability (e.g., a randomized control trial) are less indicated than efforts to test local impact (e.g., a single-group repeated-measures trial) because CBPR projects are designed purposefully to tap and reflect the unique resources and challenges of their immediate contexts.

Ultimately, participants in CBPR tend to combine both qualitative and quantitative methods. Using multiple methods over the course of a project enables researchers to triangulate different sources of data, and this increases confidence in conclusions that are drawn (Blumenthal, & DiClemente, 2013; Israel et al., 2012). Throughout this and the cyclical processes of CBPR, all data that are collected and analyzed are presented back to the initiative's participants (Hambridge, 2000; Mendenhall & Doherty, 2005; Meyer, 2000; Nichols, 1995; Seal et al., 2016). This facilitates an active and purposeful dialogue between providers, researchers, and community participants about the meaning and usefulness of data—which then informs the generation of ensuing action steps to further improve and/or maintain success in the work.

Competence in Research Ethics and Human Subjects' Protection

Anyone engaged in social science and/or biomedical research must be trained in and familiar with the culture, rules, and practices of human-subjects protection. Protecting and promoting the rights and interests of all research participants—including those who are vulnerable and susceptible to diminished or coerced consent and/or who lack (or may come to lack) the capacity to consent to or decline continued participation in investigative pursuits—is essential to the conduct of

ethical research. Work that involves protected health information further necessitates familiarity with Health Insurance Portability and Accountability Act (HIPAA) standards. In CBPR, it is especially important to maintain close collaboration (and frequent consultation) with universities'—and/or health systems'—institutional review boards (IRBs) regarding the fast-paced and ever-changing nature of community-engaged efforts. Unlike conventional research projects that may only require annual renewals after receiving an IRB's initial approval to begin, CBPR projects frequently require change-of-protocol requests/procedures, articulations (and rearticulations) of “public” versus “private” study data, and adding/removing study personnel (alongside ensuring the successful completion of indicated Collaborative Institutional Training Initiative (CITI) and HIPAA training of said personnel). In the authors' experience, monthly interactions with IRBs are commonplace.

Disseminating Scholarship Across Lay and Professional Forums

Disseminating research findings is essential when sharing scholarship and newfound wisdom with academic researchers, providers, administrators—and with patients, families, and communities—who are involved in the work. Results communicate success of the project, changes brought about by its labors, and the ongoing efforts that providers/researchers/families/community members are doing to sustain the initiative. CBPR teams, then, collaborate fully in writing and disseminate study findings to professional/scientific communities, community-specific organizations, and the general public. To share knowledge with the scientific community, they target refereed journals and local, national, and international conferences and forums. To share knowledge with community-specific organizations, the local community itself, and the general public, team members connect with community service-providing sites and resources, e.g., targeting local and state-wide public print and electronic media and community events/celebrations (Berge et al., 2009; Mendenhall, Doherty, Berge, Fauth, & Tremblay, 2013; Minkler & Wallerstein, 2008).

Community Engagement Across the MedFT Healthcare Continuum

Medical family therapy serves as a useful framework for the integration of community energies and expertise with conventional professional knowledge and contributions to program development and care services. Specific training and collaborative, teaching/mentoring, and research competencies represent important facets of this work as professionals engage in what they can feel very different than what they were trained to do in graduate school (i.e., deliver care or education in professionally led ways). Tables 14.1 and 14.2 highlight specific skills that characterize MedFTs'

Table 14.1 Medical Family Therapy in Community Engagement: Basic Knowledge and Skills

MedFT Healthcare Continuum Level	Level 1	Level 2	Level 3
Knowledge	<p>Basic knowledge about BPSS approaches to working with highly distressed individuals, couples, families, and communities.</p> <p>Basic knowledge regarding local community issues (e.g., common and/or highly prevalent health or social concerns of patient populations served).</p>	<p>Familiar with benefits of patient and family engagement with others in the community (e.g., benefits of receiving and offering support to/from others who share similar struggles).</p> <p>Basic knowledge about local community resources, including structures, leadership, and key groups and individuals.</p>	<p>Basic knowledge regarding CBPR and its value in cocreating new knowledge and interventions that are clinically useful.</p> <p>Understanding regarding interrelationships of BPSS elements in patients/families/communities’ experiences in health.</p> <p>Understanding regarding the difference(s) between conventional professional roles and identity and those of a citizen professional.</p>
Skills	<p>Can discuss (and psycho-educate) basic relationships between biological, psychological, and behavioral foci vis-à-vis common health issues.</p> <p>Collaborative skills within standard healthcare professional networks.</p>	<p>Can coordinate care with local community agency personnel inside and outside of healthcare.</p>	<p>Coordinate and integrate respective community members’ expertise and counsel into the creation of an interconnected “map” of professional and lay resources and outreach initiatives.</p>

involvement in community engagement through CBPR across Hodgson, Lamson, Mendenhall, and Tyndall’s (2014) MedFT Healthcare Continuum. As we move along the continuum, we carry different expectations regarding the appropriately matched roles, knowledge, and overall contributions to the creation of new knowledge through the iterative designing, evaluating, and refining of interventions that reflect the collective wisdom, efforts, and participation of both professional and lay team members.

At the beginning of the continuum, MedFTs at *Level 1* should possess a general understanding about BPSS approaches to working with highly distressed persons (individuals, couples, families, and communities) and be able to provide psycho-education about the ways that multiple human systems can influence and impact each other. While minimally involved in community engagement activities, they are familiar with the local cultures and concerns within the populations that their prac-

Table 14.2 Medical Family Therapy in Community Engagement: Advanced Knowledge and Skills

MedFT Healthcare Continuum Level	Level 4	Level 5
Knowledge	<p>Adept understanding of CBPR and CHC strategies (see Appendixes 1 and 2).</p> <p>Understands common lessons learned from a wide range of CBPR projects regarding initiative development, processes, timing, etc.</p>	<p>Conversant with evidence-based ways of evaluating CBPR processes and outcomes; indicated methodologies include both quantitative and qualitative traditions.</p> <p>Knowledgeable regarding CBPR project “scaffolding,” which enables new partnerships between professional and lay community members to create new initiatives with some facilitative structure and guidance (but not in a manner that undermines their natural growth and evolution).</p>
Skills	<p>Adept in the facilitation of community member/professional provider conversations regarding shared pressure points.</p> <p>Able to deliver seminars and workshops about CBPR, articulating methodological tenets and strategies.</p> <p>Can apply for and secure external grant funding by effectively communicating CBPR tenets, strategies, and processes; can negotiate adequate flexibility in grant-related timelines and deliverables so as to not sabotage the natural evolution of professional/community partnership(s).</p> <p>Consistently collaborates with key team members, working democratically through every step of CBPR’s iterative processes.</p>	<p>Able to conduct qualitative research regarding community members’ and professionals’ collaborative efforts in CBPR; foci include (but are not limited to) shared pressure points, project development, and perspectives regarding intervention components’ contributions to objective outcomes; methods include (but are not limited to) individual and group key informant interviews, observational analysis, and ethnography.</p> <p>Can conduct quantitative research that informs evaluation of a CBPR project; this can range from (but is not limited to) pilot testing of a new initiative (e.g., single group, repeated measures) to cross-group comparisons of an established program (via randomized or quasi-experimental methods).</p> <p>Teach and mentor professional and lay community members in the creation, conduct, evaluation, and refinement(s) of CBPR initiatives.</p> <p>Disseminate new knowledge, lessons learned, etc. through both professional (e.g., peer-reviewed journals, guild conferences) and lay (e.g., local news, powwows, community health fairs) arenas.</p>

tices are positioned in, such as common and/or highly prevalent health challenges (like obesity, diabetes, chronic pain, etc.) or social worries (like poverty, poor access to high-quality education, etc.)—and evidence collaborative skills within standard health professional networks (e.g., referring patients to indicated specialist sites) to address particular presenting problems.

MedFTs functioning at *Level 2* demonstrate basic community engagement by nature of their familiarity with—and encouragement regarding—the utility of peer-support processes for their patients. They maintain important knowledge about local community resources, including organizations' structures, leadership, and key individuals and groups with whom to coordinate care. While still delivering most of their services within the context of a local practice, MedFTs at this level are able to—and often do—coordinate referrals and collaborative efforts with local community agencies that are both inside (e.g., specialist sites) and outside (e.g., faith-based groups, community-led education/support initiatives) of standard healthcare.

MedFTs equipped with knowledge and skills outlined in *Level 3* are functioning as community-oriented practitioners. They are able to articulate the manners in which combining professional wisdom with patients' and communities' "lived experience" can inform the creation of new knowledge and, potentially, interventions. They understand their professional contributions to care as existing within a mosaic of collaborative assets that can combine together into a whole amounting to more than the sum of its parts. These MedFTs see themselves as citizens of the community (versus providers for it). They may or may not be actively engaged in CBPR that partners with professional and lay community members and groups but are nevertheless conceptualizing care efforts with this mindset in place. A MedFT working with Teresa, for example, could facilitate her loved ones' co-ownership of disease management within the family (e.g., shared routines in diet and exercise) and contextualize these efforts within the larger American Indian community through discussions about health disparities and/or collective efforts to engage community members in supportive forums. He or she could offer care that is consciously delivered in a manner that is mapped and integrated into a complex and interconnected milieu of professional (e.g., local American Indian serving organizations) and lay (e.g., local powwows, health fairs) resources available to Teresa and her family.

MedFTs at *Level 4* maintain high skill and knowledge in the conduct of CBPR. They have generally gained these competencies through both textbook and real-life applications of such collaborative work. As experts in community engagement, they are familiar with common lessons learned (e.g., those regarding the often messy and unpredictable pace of CBPR projects, the importance of administrative support through institution champions; see [Appendix 1](#)) in this work and are able to advance strategies in collaborative leadership and team efforts that are essential to project development and sustainability (e.g., democratic planning at every step, folding new learning back into the community; see [Appendix 2](#)). Equipped with these understandings and skill sets, MedFTs at this level are able to construct compelling proposals for external monies to support the work. A MedFT working with Teresa and the FEDS project, for example, could effectively collect and integrate pilot data

into the construction of a proposal to fund more extensive evaluation of a community's participation in the work. This grant writing would be carried out in a manner that carefully honors researchers' wants for objective outcome data, community participants' voices in identifying what data are most relevant to collect (and how to collect said data), and funders' wants for clear timelines and deliverables (vis-à-vis the comparative ambiguities of CBPR's natural evolution). These efforts would be carried out with purposeful timing so as to not sabotage a project's evolution (e.g., applying for funding to formally evaluate the FEDS project after it has been created and achieved initial stability versus during its early planning stages).

MedFTs who function at *Level 5* are leaders in community engagement. They maintain in-depth familiarity with CBPR literature relevant to their field(s) of practice, alongside extensive experience in the conduct and iterative processes of evaluating and refining CBPR programs that demonstrate both clinical utility and temporal sustainability. They are well positioned to teach (usually via observational and consultative mentoring over 1–2 years' time) professional and lay community members in how to conduct CBPR of their own. Their knowledge regarding the theoretical and methodological underpinnings and tactics in CBPR equips this teaching with ready "scaffolding" for community projects. These MedFTs are thereby able to foster and grow new partnerships between professional and lay team members in manners that are more efficient as compared to beginning an initiative "from scratch" while at the same time not bypassing important steps in a unique project's evolution or dishonor (or miss) the unique needs, challenges, resources, and strengths of the community in which novel efforts are positioned. Their investigative competencies include both qualitative and quantitative methods, as a broad range of evaluative methodologies are indicated over the course of any CBPR project's lifespan. A MedFT at this level is able to, for example, conduct key informant interviews with Teresa and other community members to assess (via thematic analyses) common and shared viewpoints regarding which components of a complex intervention are most influential to positive health outcomes that have already been quantitatively confirmed through single-group, repeated-measures assessments during a project's pilot phases (and/or later via experimental or quasi-experimental comparisons of intervention and control/wait-list participants). He or she disseminates new knowledge and lessons learned across both professional (e.g., referred journals, guild conferences) and lay (e.g., local health fairs, news stories) arenas.

Research-Informed Practices

Since the early 1990s, CBPR has evolved from a fringe science of sorts to one of established credibility across the helping professions (e.g., primary care, nursing, public health, behavioral health). It has served to increase understanding of patients' and their loved ones' experiences with a wide variety of health struggles, inform the design and/or improvement of healthcare services, facilitate community outreach and participation in health activities, and improve health-related education

(Coughlin, Smith, & Fernandez, 2017; Seal et al., 2016; Tobin, 2000; Ward & Trigler, 2001).

More healthcare providers and researchers—many of whom identify as MedFTs—are engaging in CBPR projects nowadays than ever before (Dombrowski, 2016; Ivankova, 2015; Mendenhall, Pratt, Phelps, Baird, & Younkin, 2014). As they do this, rigorous expert-driven investigatory methods aimed at widespread generalizability are losing ground to comparatively small but locally relevant and meaningful efforts that are cocreated by patient and provider communities working collaboratively toward shared goals. This evolution is advancing in synchrony with our increased emphases on patient/family-centered healthcare homes (Abdouch, 2017; Stange et al., 2010), wherein comprehensive approaches for children, youth, and adults are attended to within settings that facilitate partnerships between individuals/families and respective (and collaborating) members of interdisciplinary care teams (Minkler & Wallerstein, 2008; Peek, 2011; Wallerstein & Duran, 2010). Through CBPR methods, the patient/family community partnerships with providers are held up as an essential foundation to create care that is high quality, culturally competent, strengths based, and effective (Chavez, Duran, Baker, Avila, & Wallerstein, 2003; Doherty et al., 2010; Israel et al., 2012).

Exhaustively reviewing or presenting all outcome studies in CBPR is beyond the scope of this chapter, insofar as the approach has been employed across dozens of professional fields targeting innumerable topics and challenges. Echoing this widespread visibility and scope, CBPR within healthcare professions has been advanced and evaluated across a range of health foci, including (but not limited to) obesity (Berge et al., 2016; Davison, Jurkowski, Li, Kranz, & Lawson, 2013), diabetes (Doherty et al., 2010; Mendenhall & Doherty, 2005), healthy diet (DeHaven et al., 2011; Smith, Mateo, Morita, Hutchinson, & Cohall, 2015), smoking cessation (Mendenhall et al., 2011; Mendenhall et al., 2008), asthma (Brugge et al., 2010; Garwick & Auger, 2003), dental and mouth-care practices (Park et al., 2017; Walker et al., 2017), accident reduction (Brunette & Ibarra, 2009; Gallagher & Scott, 1997), safe sexual practices (Stevens & Hall, 1998; Rhodes et al., 2011), midwifery (Barrett, 2011; Foster, Chiang, Hillard, Hall, & Heath, 2010), living with disabilities (Hassouneh, Alcalá-Moss, & McNeff, 2011; Ravesloot, 2016), child and adolescent mental illness (Breland-Noble, Bell, & Nicolas, 2006; Gewirtz, 2007; Novins et al., 2012), and overall physical well-being (Davis & Reid, 1999; Ferrera et al., 2015; Hampshire et al., 1999; Kondrat & Julia, 1998; Lewis, Sallee, Trumbo, & Janousek, 2010; Lindsey & McGuinness, 1998; Meyer, 2000; Schulz et al., 2003).

The inclusion and engagement of family members and/or close friends across this work is visible—and arguably essential—because many health-related foci are situated in the everyday lifestyles, routines, and habitudes carried out within the social systems that patients inhabit. Indeed, it is easier for patients—like Teresa—to adopt new healthy habits (e.g., diet, exercise) and/or to discontinue old unhealthy habits (e.g., smoking, sedentariness) if the people they are most close to change their behaviors in synchrony. Doing this in a broader community context of other engaged patients, families, and friends—like in the FEDS project—further supports a collective energy and investment facilitative of beneficent change. It is upon these

grounds that MFTs and MedFTs—as systems thinkers, practitioners, scholars, and citizens—are uniquely equipped to learn and advance CBPR (Doherty et al., 2010; Mendenhall & Doherty, 2005; Mendenhall et al., 2013, 2014).

Conclusion

The greater vision for community-engaged care and scholarship is to create models of healthcare, education, and outreach as work that is by and for its citizens, with all stakeholders—including patients, families, healthcare providers, and other community members—working together. MedFTs—equipped with behavioral and relational skills in care provision and scholarship—represent a valuable addition to these teams. Emerging evidence supports their contributions (specifically) and CBPR (generally). As this type of work continues to advance across both depth and scope, professional providers/researchers and lay communities will increasingly create effective interventions that neither could create alone. Working within the contexts of flattened hierarchies and with a mindset that values everyone’s respective wisdom and contributions, we will ultimately advance better care and improved health.

Reflection Questions

1. How can you, as a MedFT, incorporate CBPR values of tapping community members’ lived experience and wisdom into the work that you do in everyday practice?
2. What are the pressure points (i.e., concerns shared by both professional service providers and the communities that they serve) in the context(s) of your own practice?
3. What type of CBPR initiative could you potentially engage in via professional/community partnerships through your university, workplace, or practice? How could you begin conversations and steps toward doing this?

Additional Resources

Literature

- Blumenthal, D. S., & DiClemente, R. J. (Eds.). (2013). *Community-based participatory health research: Issues, methods, and translation to practice*. New York, NY: Springer.
- Coughlin, S., Smith, S., & Fernandez, M. (Eds.) (2017). *Handbook of community-based participatory research*. New York, NY: Oxford University Press.
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- Ivankova, N. V. (2014). *Mixed methods applications in action research*. Los Angeles, CA: Sage.
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Organizations/Associations

- Colorado School of Public Health's Rocky Mountain Prevention Research Center. <http://www.ucdenver.edu/academics/colleges/PublicHealth/research/centers/RMPRC/training/Pages/CBPR.aspx>
- Detroit Community-Academic Urban Research Center. <http://detroitcenter.umich.edu/projects/detroit-community-academic-urbanresearch-center>
- University of Chicago's Institute for Translational Medicine. <http://itm.uchicago.edu/community-based-participatory-research/>
- University of Minnesota's (UMN) Citizen Professional Center. www.citizenprofessional.org
- University of New Mexico's (UNM) Center for Participatory Research. <http://cpr.unm.edu/>

Appendix 1: Strategies for CBPR and Citizen Health Care¹

1. Get buy-in from key professional leaders and 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 healthcare setting. However, we have found it best to request little or no budget, aside from a small amount of staff time, in order to allow the project enough incubation time before being expected to justify its outcomes.

2. Identify a health issue that is of great concern to both professionals and members of a specific community (clinic, neighborhood, cultural group in a geographical location).

Stated differently, the issue must be one that a community of citizens actually cares about—not just something that we think they should care about. The professionals initiating the project must have enough passion for the issue to sustain their efforts over time.

3. Identify potential community leaders who have personal experience with the health issue and who have relationships with the professional team.

¹Source: Doherty, W., Mendenhall, T., & Berge, J. (2010). The families & democracy and citizen healthcare project. *Journal of Marital and Family Therapy*, 36, 389–402. <https://doi.org/10.1111/j.1752-0606.2009.00142.x>

These leaders should generally be ordinary members of the community who in some way have mastered the health issue in their own lives and who 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, because they bring institutional priorities and constraints.

4. *Invite a small group of community leaders (3 to 4 people) to meet several times with the professional team to explore the issue and see if there is a consensus to proceed with a larger community project.*

These are preliminary discussions to see if a Citizen Health Care project is feasible and to begin creating a professional/citizen leadership group.

5. *This group decides on how to invite a larger group of community leaders (10–15) to begin the process of generating the project.*

One invitational strategy we have used is for providers to nominate patients and family members who have lived expertise with a health issue and who appear to have leadership potential.

6. *Over the next 6 months of biweekly meetings, implement the following steps of community organizing:*

- (a) *Exploring the community and citizen dimensions of the issue in depth*
- (b) *Creating a name and mission*
- (c) *Doing one-to-one interviews with a range of stakeholders*
- (d) *Generating potential action initiatives, processing them in terms of the Citizen Health Care model and their feasibility with existing community resources*
- (e) *Deciding on a specific action initiative and implementing it*

7. *Employ the following key Citizen Health Care processes:*

- (a) *Democratic planning and decision-making at every step.* As mentioned before, this requires training of the professionals who bring a disciplined process model and a vision of collective action that does not lapse back into the conventional provider/consumer model, but who do not control the outcome or action steps the group decides to take.
- (b) *Mutual teaching and learning among community members.* Action initiatives consistent with the model first call upon the lived experience of community members, with the support of professionals, rather than recruiting community members to support a professionally created initiative.
- (c) *Creating ways to fold new learnings back into the community.* All learnings can become “community property” if there is a way for them to be passed on. Currently we have vehicles for professionals to become “learning communities,” but few vehicles outside of Internet chat rooms for patients and families to become learning communities.
- (d) *Identifying and developing leaders.* The heart of community organizing is finding and nurturing people who have leadership ability but who are not necessarily heads of organizations with turfs to protect.

- (e) *Using professional expertise selectively—“on tap,” not “on top.”* In this way of working, all knowledge is public knowledge, democratically held and shared when it can be useful. Professionals bring a unique font of knowledge and experience—and access to current research—to Citizen Health Care initiatives. But everyone else around the table also brings unique knowledge and expertise. Because of the powerful draw of the provider/consumer way of operating, professionals must learn to share their unique expertise when it fits the moment, and to be quiet when someone else can just as readily speak to the issue. A community organizing axiom applies here: Never say what someone in the community could say, and never do what someone else in the community could do.
- (f) *Forging a sense of larger purpose beyond helping immediate participants.* Keep the Big, Hairy, Audacious Goal (BHAG) in mind as you act in a local community. Citizen Health Care is not just about people helping people; it is about social change toward more activated citizens in the healthcare system and larger culture. This understanding inspires members of the Citizen Health Care project about the larger significance of their work. It also attracts media and other prominent community members to seek to understand, publicize, and disseminate Citizen Health Care projects.

Appendix 2: Lessons Learned in CBPR and Citizen Health Care²

1. This work is about identity transformation as a citizen professional, not just about learning a new set of skills.
2. It is about identifying and developing leaders in the community more than about a specific issue or action.
3. It is about sustained initiatives, not onetime events.
4. Citizen initiatives are often slow and messy, especially during the gestation period.
5. You need a champion with influence in the institution.
6. Until grounded in an institution's culture and practices, these initiatives are quite vulnerable to shifts in the organizational context.
7. A professional who is putting too much time into a project is over-functioning and not using the model. We have found that the average time commitment to be on the order of 6–8 hours/month, but over a number of years.
8. 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.

²Source: Doherty, W., & Mendenhall, T. (2006). Citizen health care: A model for engaging patients, families, and communities as co-producers of health. *Families, Systems, & Health, 24*, 357–362. <https://doi.org/10.1037/1091-7527.24.3.251>

9. The pull of the traditional provider/consumer model is very strong on all sides; democratic decision-making requires eternal vigilance.
10. You cannot learn this approach without mentoring, and it takes 2 years to get good at it.

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