The Family Education Diabetes Series (FEDS): community-based participatory research with a midwestern American Indian community

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Indigenous people around the globe tend to struggle with poorer health and well-being than their non-indigenous counterparts. One area that this is especially evident is in the epidemic of diabetes in North America’s American Indians (AIs) – who evidence higher prevalence rates and concomitant disease-related complications than any other racial/ethnic group. As researchers and AI communities work together to transcend conventional top-down, service-delivery approaches to care, community-based participatory research is beginning to show promise as a way to partner contemporary biomedical knowledge with the lived-experience, wisdom, and customs of Indigenous people. This study describes the Family Education Diabetes Series (FEDS) as an example of such effort, and highlights pilot findings assessing its value and impact across key diabetes-relevant variables. Following 36 intervention participants across baseline, 3-month, and 6-month time periods, data show significant improvements in weight, blood pressure, and metabolic control (A1c). Strengths and limitations of this investigation are presented, along with suggestions about how to further advance and empirically test the work across other Indigenous communities.

Key words: action research, American Indians, community-based participatory research, diabetes, indigenous people, obesity.

Indigenous people around the globe tend to struggle with poorer physical health and well-being than their non-indigenous counterparts. One area that this is especially evident is in the epidemic of diabetes in North America’s American Indians (AIs) – who evidence higher prevalence rates and concomitant disease-related complications than any other racial/ethnic group. As researchers and AI communities work together to transcend conventional top-down, service-delivery approaches to care, community-based participatory research (CBPR) is beginning to show promise as a way to partner contemporary biomedical knowledge with the lived-experience, wisdom, and customs of Indigenous people. The Family Education Diabetes Series (FEDS) was designed and implemented through a CBPR approach involving local elders and leaders in a Midwestern United States AI community and healthcare providers and researchers affiliated with the University of Minnesota (UMN) Medical School. The main aim of this study is to describe and report pilot data from this innovative project.
DISPARITIES IN INDIGENOUS HEALTH

The world’s Indigenous people span every inhabited continent on the globe and encompass thousands of cultures, ethnicities, religions, languages, and mores. And although the rich diversities within these groups are integral to their unique and respective identities, all share in the profound adversities they have endured through the colonization of their people and lands by powerful outsiders who later dominated them and eradicated (or attempted to eradicate) their ways of life (Gracey and King 2009). Of the estimated 370–400 million Indigenous people in the world today, almost all are over-represented among the disadvantaged and poor, and their overall health and well-being is comparatively worse than their non-indigenous counterparts. From high infant mortality to shortened total life expectancy, to diseases and deaths caused by cigarette smoking, alcohol and drug abuse, unhealthy lifestyles (e.g., obesity, hypertension, diabetes), and environmental contaminations – Indigenous people are the hardest hit (Gracey and King 2009; King, Smith, and Gracey 2009).

Indigenous health in North America

North America’s (including Canada and the United States) Indigenous people, known collectively as ‘Native Americans’, include more than 560 recognized tribes and groups (e.g. Canada’s First Nation, Metis, and Cree; US Lakota, Sioux, Ojibwe) (King, Smith, and Gracey 2009). Their health status is consistent with Indigenous groups’ health trends across the world, insofar as they fare worse in nearly every physical and mental health category that is documented compared to their non-indigenous counterparts (Chateau-Degat et al. 2009; Kahn and Khan 2009; King, Smith, and Gracey 2009; Oster and Toth 2009; Roberts et al. 2009). Principal reasons attributed to this are myriad, including (but not limited to) poverty, malnutrition, poor hygiene, overcrowding, and poor access to preventive health services (Roberts et al. 2009). Increased urbanization is especially noteworthy as it relates to lifestyle problems (e.g. obesity, diabetes), and as engagement in physical activity declines and consumption of highly processed and fatty foods increases. Hereditary factors associated with populations of hunter-gatherers are also viewed as contributing to these disparities vis-à-vis contemporary trends in urbanization; explanations have been proposed about how Native Americans survived sporadic food availability under feast-or-famine conditions through rapid and elevated insulin secretion and excessive caloric intake. These hypotheses are continually evolving as our understanding of metabolism and diabetes mellitus evolves (Bindon and Baker 1997; National Diabetes Information Clearing House (2002); King 2004).

American Indians and diabetes

Across both the United States and Canada, diabetes is recognized as one of the most widespread lifestyle-related diseases affecting Native Americans – and it is to this issue that the present investigation was focused. Aligning closely with epidemiological data in its sister North American country of Canada, current prevalence estimates for diabetes in the USA exceed 7% of the general population (Centers for Disease Control and Prevention 2009; National Heart Lung and Blood Institute 2004; National Institute of Diabetes and Digestive and Kidney Diseases 2007). Disparities in health status related to diabetes and its myriad complications and eventual sequelae are well documented; the AI population – referring to the estimated 2.5 million Native Americans residing in the USA – is especially affected, with prevalence rates as high as 50% among some tribes (Rhoades and Buchwald 2003; Indian Health Service 2005; United States Census Bureau 2010) alongside higher rates of disease-related complications such as co-morbid heart disease, reduced or lost vision, amputations, kidney disease, and depression compared to Caucasian and all other racial/ethnic groups (Indian Health Service 2005; National Institute of Diabetes and Digestive and Kidney Diseases 2007; Sahmoun, Markland, and Helgerson 2007; Jiang et al. 2008, 427).

Diabetes interventions for American Indians

The healthcare industry has struggled to successfully reach the AI community though traditional care delivery systems (WhiteEagle 2005). In prior studies of type 2 diabetes control in the AI population, interventions did include a component of basic education regarding AI culture (e.g. traditional foods; e.g. Ponchilla 1993; LeMaster and Connell 1994; Carter et al. 1997; Hood et al. 1997; Gilliland et al. 2002; Keltner, Kelley, and Smith 2004); however, these initiatives primarily targeted lifestyle changes and medical management of the disease – that is, traditional healthcare delivery – rather than working to increase ‘ownership’ of the problem by individual patients, families, and communities. Advancing diabetes management within the AI community is an under-researched area.

Another notable gap is that most research has been conducted with AIs living on reservations. This is due, at least in part, to the presence of the Indian Health Service (IHS) and researchers’ want for recruiting large homogeneous samples. Urban-dwelling AIs have been largely overlooked in diabetes
studies; this is problematic because it is increasingly common for AIs to live in metropolitan settings, and (as outlined above) because urban-dwelling AIs generally have poorer health and greater health disparities than those living on reservations (Urban Indian Health Institute 2004; White Eagle 2005). Up to 70% of AIs now reside outside of reservations; the few studies that have been conducted on their health indicate that large segments of this group experience considerable difficulties in obtaining primary and preventive health-care as a consequence of their socioeconomic condition and the absence of IHS in many urban areas (Taylor 1988; Kramer 1992; Rhodeas and Buchwald 2003; Urban Indian Health Institute 2004). Only recently have efforts in community engagement and provider–patient partnerships in the AI community been attempted with the urban AI community; these are relatively new and require more development (Mendenhall 2002; Doherty and Mendenhall 2006).

Many providers and communities of patients are now looking to (and engaging in) novel and collaborative partnerships that honor and tap resources across professional and patient groups alike – and to position these efforts in the very communities that diabetes is of most concern. CBPR, described in more detail below, represents a leading methodology herein as it emphasizes close collaboration between professional researchers and lay community members (Lewin 1946; Minkler and Wallerstein 2003; Mendenhall and Doherty 2005). Hierarchical differences are flattened through this partnership as all participants work together to generate knowledge and solve local problems. Principal reasons justifying this approach rest in its contrast to AI people’s experience with conventional research (i.e. conducted by outsiders through top-down, expert-driven methods) that has tended to benefit researchers more than AIs (e.g. professional prestige, tenure), pathologized AIs as dysfunctional, and not directly informed or advanced the communities they were supposed to help (e.g. study results not shared with AIs) (Davis and Reid 1999; Burhanstipanov, Christopher and Schumacher 2005; Gone 2006). Emerging CBPR projects in AI communities, while still focusing on children more than adults, support the utility of CBPR efforts in co-creating medically sound programs that are sensitive to local customs and cultural traditions (Steckler et al. 2002; Garwick and Auger 2003; Potvin et al. 2003; Castro et al. 2009). The FEDS was designed and implemented through a CBPR approach involving local elders and leaders in the AI community through the St Paul Area Council of Churches’ Department of Indian Work (DIW) and healthcare providers and researchers affiliated with the UMN Medical School. Targeting urban-dwelling AIs in the Twin Cities of Minneapolis/St Paul, the FEDS represents a purposeful integration of western medicine and AI cultures. The main aim of this study is to describe and report pilot data from the FEDS project.

**COMMUNITY-BASED PARTICIPATORY RESEARCH**

Since its early coining of ‘action research’ by Kurt Lewin in the 1940s, many have contributed to advancing an investigative orientation wherein academic and professional researchers partner and collaborate with communities who are directly affected by an issue to generate knowledge and solve local problems (Lewin 1946, 34; Agency for Healthcare Research and Quality 2004; Mendenhall and Doherty 2005; Berge, Mendenhall, and Doherty 2009). Approaches within this larger frame vary in and across the degrees to which professionals and community members are involved in facilitating group processes, engaged in decision-making and change sequences, and roles/experiences as (co)learners (Cornwall and Jewkes 1995; Bell et al. 2004; Wallerstein and Duran 2006), and have been recognized by unique and overlapping terminologies and labels like ‘participative research’ and/or ‘participatory research’ (PR), ‘participatory action research’ (PAR), ‘development leadership teams in action’ (DETA), ‘critical action research’, ‘collaborative inquiry’, ‘co-operative research’, ‘appreciative inquiry’ and others that purposively exclude the word ‘research’ so as to emphasize learning and change processes per se (e.g. ‘participatory action learning’, ‘participatory action development’) (Rahman and Fals-Borda 1991, 24; Kemmis and McTaggart 2000, 567; Heron and Reason 2001, 179; Kelly, Mock, and Tandon 2001, 348; Ludema, Cooperrider, and Barrett 2001, 189; Pyrch and Castillo 2001, 379; Bell et al. 2004, 10; Torre and Fine 2005, 221; Baum, MacDougall, and Smith 2006, 854; Byrne and Sahay 2006, 71; Braithwaite et al. 2007, 61; Pyrch 2007, 199; Wilson, Ho, and Walsh 2007, 85; Cammarota and Fine 2008, 1; Classen et al. 2008, 2402). As large national and international organizations focused on health (e.g. Agency for Healthcare Research and Quality; National Institutes for Health, World Health Organization) have systematically called for – and advanced funding to support – community-driven and collaborative efforts to address complex health and social problems ill-suited for conventional top-down service delivery and research endeavors, ‘community-based participatory research’ (CBPR) has been put forth alongside ‘action research’ as an inclusive and characterizing ‘umbrella’ to connect these like-minded efforts (Agency for Healthcare Research and Quality 2004; Pan American Health Organization 2004; Edwards et al. 2008, 188; Bogart and Uyeda 2009).
Several key assumptions permeate CBPR projects, including: (i) recognition of the community as the principal unit of identity; (ii) democratic and equitable partnership between all project members (e.g., participants, community stakeholders, researchers) as collaborators through every stage of knowledge and intervention development; (iii) building on the strengths and resources within the community; (iv) promoting co-learning and capacity-building between and among partners; (v) deep investment in change that carries with it an element of challenging the status quo and improving the lives of members in a community or practice; (vi) cyclical process in which problems are identified, solutions to address problems are developed within the context(s) of the community’s existing resources, interventions are implemented, outcomes are evaluated according to what is essential in the eyes of participants, and interventions are modified in accord with new information as necessary; (vii) project members’ humility and flexibility to accommodate changes as necessary across any part of a project; (viii) disseminating findings and new knowledge to and by all partners and constituents in the investigative process; (ix) recognition that CBPR can be a slow and messy process, especially during initial phases of development; and (x) long-term engagement and commitment to the work (Bradbury and Reason 2003; Mendenhall and Doherty 2005; Strickland 2006; Scharff and Mathews 2008; LaVeau and Christopher 2009; Doherty, Mendenhall, and Berge in press).

Community-based participatory research has gained credibility in medicine, nursing, public health, and behavioral health since the early 1990s because of its ability to inform understanding of patients’ experiences, improve or generate services, facilitate community outreach and engagement, enhance education, and augment cultural awareness (Mendenhall and Doherty 2007; Tobin 2000; Ward and Trigler 2001; Chavez et al. 2003). Projects carried out through this method have effected improvements in asthma, dental and mouth-care practices, management of preoperative fasting, patient problem-solving skills, overall physical well-being, patient and practitioner satisfaction, patient-practitioner communication, and a number of other significant healthcare foci (Lindsey and McGuinness 1998; Hampshire et al. 1999; Meyer 2000; Schulz et al. 2003; Mendenhall and Doherty 2005; Brugge et al. 2010; Lewis et al. 2010; Doherty, Mendenhall, and Berge in press).

The Citizen Health Care Model was designed purposefully as a CBPR method for medical and mental health professionals who work with families in community settings (Doherty and Mendenhall 2006; Berge, Mendenhall, and Doherty 2009; Doherty, Mendenhall, and Berge in press).

<table>
<thead>
<tr>
<th>Table 1 Citizen Health Care Model core principles</th>
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<tbody>
<tr>
<td>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.</td>
</tr>
<tr>
<td>People must be engaged as co-producers of health-care for themselves and their communities, not just as patients or consumers of services.</td>
</tr>
<tr>
<td>Professionals can play a catalytic role in fostering citizen initiatives when they develop their public skills as citizen professionals in groups with flattened hierarchies.</td>
</tr>
<tr>
<td>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.</td>
</tr>
<tr>
<td>Local communities must retrieve their own historical, cultural, and religious traditions of health and healing, and bring these into dialog with contemporary medical systems.</td>
</tr>
<tr>
<td>Citizen health initiatives should have a bold vision (a BHAG – a big, hairy, audacious goal) while working pragmatically on focused, specific projects.</td>
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</table>

Citizen Health Care begins with the notion that all personal health problems can also be seen as public problems. For example, ethnic disparities in diabetes 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 possess important knowledge and skills. This approach emphasizes close collaboration among researchers and community participants in knowledge-generation and problem-solving. Tables 1 and 2 outline the main principles and action strategies of this model. See Doherty and Mendenhall (2006) and Doherty, Mendenhall, and Berge (in press) for a complete review.

**METHOD**

The FEDS was designed and implemented through a CBPR approach involving local elders and leaders in a midwestern United States AI community and healthcare providers and researchers affiliated with the UMN Medical School. The following is a description of the initiative’s evolution, which follows the general sequence of steps and CBPR action strategies informed by the Citizen Health Care Model (outlined in table 2) and early pilot data.
Table 2 Action strategies for citizen health-care

<table>
<thead>
<tr>
<th>Action strategy</th>
<th>Rationale</th>
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<tbody>
<tr>
<td>Get buy-in from key professional leaders and administrators</td>
<td>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, 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.</td>
</tr>
<tr>
<td>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)</td>
<td>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’.</td>
</tr>
<tr>
<td>Identify potential community leaders who have personal experience with the health issue and who have relationships with the professional team</td>
<td>Leaders should be ordinary members of the community who in some way have mastered the selected health issue in their own lives and 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 and constraints.</td>
</tr>
<tr>
<td>Invite a small group of community leaders (three or four 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</td>
<td>These preliminary discussions help determine whether a Citizen Health Care project is feasible and begin creating a professional/citizen leadership group.</td>
</tr>
<tr>
<td>Strategize how to invite a larger group of community leaders (10–15) to begin the process of generating the project</td>
<td>You must have a larger group invested in the process to facilitate a larger ‘We’ focus.</td>
</tr>
<tr>
<td>Over the next 6 months have biweekly meetings using community organizing principles</td>
<td>The following key steps are crucial, but can be slow and messy: (i) explore the community and citizen dimensions of the issue; (ii) create a name and mission statement for the initiative; (iii) conduct one-on-one interviews with a range of stakeholders; (iv) generate potential action initiatives and process them in regards to the Citizen Health Care Model and existing community resources; (v) decide on a specific action initiative and implement it.</td>
</tr>
<tr>
<td>Employ Citizen Health Care processes throughout the project</td>
<td>The following steps will keep the initiative focused, strong, and increase sustainability: (i) democratic planning and decision-making at every step; (ii) mutual teaching and learning among community members; (iii) creating ways to fold new learnings back into the community; (iv) identifying and developing leaders; (v) using professional expertise selectively – ‘on tap’, not ‘on top’; (vi) forging a sense of larger purpose.</td>
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Establishing buy-in from key professional leaders and administrators

American Indian community leaders and tribal elders in the cities of Minneapolis and St Paul, Minnesota were worried about the ever-increasing prevalence of diabetes and its impact on their people. Through their administrative positions of power in the local St Paul Area Council of Churches’ DIW and its collaborative relationships with a wide variety of community initiatives and healthcare sites oriented to serving their community, these leaders/elders grew even more alarmed by the acquiescent sense of defeat that they were...
hearing from those affected. Many AIs communicated to them (and to each other) that diabetes is to be expected — that it cannot be prevented because it is a ‘curse’ unto AI people. Professional leaders and administrators in the medical community — positioned across a range of healthcare sites serving a variety of clientele — were also becoming increasingly worried about their AI patients. What they were seeing echoed what they were reading about in professional and epidemiological literature: (i) AIs — as a group — were the hardest hit with obesity and diabetes compared to all other racial/ethnic groups; (ii) large segments — almost 50% — of the state’s estimated 54,000 AI residents were residing in urban areas outside of the scope of readily accessible healthcare through IHS (American Indian Policy Center 2010; United States Census Bureau 2010); and (iii) nobody was feeling effective in their education and/or intervention efforts designed to improve AIs’ health. In early 2001, as leaders/elders and administrators/providers across both community and medical sites discussed their respective and overlapping concerns, they agreed to begin working together to create something that neither could create by themselves.

Identifying the health issues: diabetes and obesity

Although diabetes per se seemed like an obvious and unanimously agreed upon health issue to focus on at the outset, a great deal of discussion (spanning several meetings) between the aforementioned administrators/providers and community elders/leaders took place before proceeding to the project’s next developmental steps. The question ‘Is this a problem?’ was posed and considered, evaluating whether diabetes as a disease was something that the AI community shared in perceiving as problem alongside key AI and healthcare leaders. As these conversations proceeded, ‘diabetes’ was framed as including ‘pre-diabetes’ (defined here as people at risk for developing the disease by nature of their current health status) and within this frame, especially, those struggling with obesity. AI children in single-digit ages (e.g. 4 or 5 years old) weighing as much as 100 pounds, and adults and children alike maintaining BMI indexes >40 were discussed as commonplace, and the health issues (plural) of this group’s early conversations evolved to include both diabetes and obesity as of elemental focus.

Identifying community leaders

As the group continued its work together, it identified potential leaders in the AI community who — despite so many of the odds recognized to be against them as AI people — had triumphed in controlling their weight and/or diabetes. These select few were identified through personal relationships with administrative leaders/elders and/or by nature of their public visibility as already-established and recognized persons looked up to within their local community (e.g. through the DIW itself, though local AI organizations) or healthcare/professional team. Through personal and group conversations about burgeoning ideas to ‘do something’ in the AI community regarding diabetes and obesity, these new leaders’ want to participate and ‘give back’ to the AI people was affirmed and established.

Meetings with community leaders

Early meetings between select providers/professionals (two nurses, a physician, a mental health professional) and AI community leaders (two women and one man — all recognized as local elders who had effectively worked to improve their own health) ensued, during which time the issues of diabetes and obesity in the AI community were discussed in-depth. The group shared in its frustration with the failures of conventional care (e.g. primary-care clinics), educational programs (e.g. clinic- or school-sponsored diabetes education/classes), and community-outreach (e.g. pow-wows in which diabetes awareness-raising efforts were a part). As these providers and AI community leaders (authors of this study) continued to discuss past efforts and potential new directions in their respective and overlapping efforts oriented to diabetes, they decided to approach this challenge with a CBPR approach, using the Citizen Health Care Model as a guide.

Meetings with professional/citizen leadership group

Our original (small) group of engaged providers and community leaders then worked together to invite others into its conversations regarding diabetes and obesity in the AI community. In a similar manner to the way(s) that early community leaders were identified, members in this professional/citizen leadership group were recruited on the basis of their having personal experiences and stakes in the AI community around issues of diabetes/obesity.

Over the course of this early and ongoing work, considerable effort was spent in designing a partnership that was different than conventional top-down models of care. Community members worked to sensitize providers and clinical researchers to the process(es), pace, and importance of building trust within AI circles. As the team engaged in a
series of meetings (twice a month for 6 months), group discussions, and AI community events, this trust evolved. Providers and researchers learned about AI culture, the diversity of cultures/tribes within this larger frame (e.g. Dakota, Ojibwe, Hocak), belief systems, and manners— all because they were allowed into the AI community itself. In turn, community members gained more insights into and regarding how western medicine is oriented, and thereby secured better understanding(s) into providers’ habits and perspectives in care delivery.

This process took approximately 2 years to evolve and transpire, which is consistent with established literature regarding the development of authentic, trusting, and effective CBPR partnerships between professional providers/researchers and Indigenous people (Minkler et al. 2003; Burhanstipanov, Christopher, and Schumacher 2005). Our group (which eventually re-named itself the ‘citizen action group’) then worked collaboratively to develop the FEDS, organize recruitment strategies, consider and identify outcome measures, implement the intervention, collect data, and disseminate findings across professional and lay audiences and outlets.

**Program description**

The FEDS was first launched in 2003. Within the program, patients, their families (spouses, parents, children), and providers (physicians, nurses, dieticians, mental health personnel) are brought together and assembled every other week for an evening of fellowship, education, and support for 6 months. Generally six to seven providers, four to five tribal elders, and 35–40 community members attend. Meetings begin with members checking and recording each other’s blood sugars, weight, and conducting foot checks. Participants cook and eat meals together that are consistent with AI cultures and traditions and discussion follows regarding the meal’s ingredients, cost and availability, portion sizes, and relevance to diabetes and healthy weight maintenance. Educational sequences follow (which, consistent with CBPR methods/sequences, are planned and designed a priori according to participants’ interests and wants), and take place in education and talking circles and a variety of lively activities consistent with AI cultures (e.g. traditional and modern music and drumming, chair dancing and aerobics, creative arts, impromptu theater/role plays). Instructional topics are similarly diverse, including: basic diabetes education, obesity and weight loss, foot care, stress management, exercise, family relationships, retinopathy, dental care, and resources to facilitate access to medical services and supplies (see table 3). FEDS evenings conclude with devoted time for informal sharing and support. These bi-weekly series are scheduled to last for three hours, but most participants arrive early and stay late.

**Pilot evaluation and testing**

Although anecdotal reports of success have been common throughout the FEDS series, in 2008 we systematically followed participants through an entire program sequence to formally assess for quantitative change in key diabetes-relevant variables. Our guiding research question, which was developed and agreed upon by the citizen action group, was: Do participants in the FEDS program evidence change in their physical health, as measured by metabolic control (A1c), blood pressure, and weight? To answer this question, we tracked and analyzed data from baseline, 3- and 6-month follow-up (i.e. from the beginning to the conclusion of the program). Our efforts in doing this were reviewed and approved by the UMN’s Institutional Review Board (IRB) and Human Research Protection Program (HRPP).

Consent processes followed standardized IRB/HRPP sequences in which participants were provided and oriented to the following: the project’s purpose and who it was being

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**Table 3** FEDS’ session topics

<table>
<thead>
<tr>
<th>Topic</th>
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<tbody>
<tr>
<td>Basic diabetes education and introduction</td>
</tr>
<tr>
<td>Diabetes in the AI community</td>
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<tr>
<td>Staying motivated with healthy habits</td>
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<tr>
<td>Dietary guidelines and portion sizes</td>
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<tr>
<td>Stress management and strategies</td>
</tr>
<tr>
<td>Fighting depression and despair</td>
</tr>
<tr>
<td>Exercise and physical activity (outdoors)</td>
</tr>
<tr>
<td>Exercise and physical activity (indoors)</td>
</tr>
<tr>
<td>Obesity and weight control</td>
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<tr>
<td>Foot care</td>
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<tr>
<td>Wound care</td>
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<tr>
<td>Blood glucose monitoring and control</td>
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<tr>
<td>Dental Care (teeth and gums)</td>
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<tr>
<td>Retinopathy/eye diseases</td>
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<tr>
<td>Keeping your kidneys healthy</td>
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<tr>
<td>Blood pressure and cholesterol</td>
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<tr>
<td>Heart disease and stroke</td>
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<tr>
<td>Gastroparesis</td>
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<tr>
<td>Neuropathy</td>
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<tr>
<td>Diabetes-related emergencies</td>
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<tr>
<td>Medical services and supplies</td>
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<tr>
<td>Working with your doctors</td>
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<tr>
<td>Family relationships/social support</td>
</tr>
<tr>
<td>Review/celebration of program</td>
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</tbody>
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conducted by; the project’s (aforementioned) research question; background information justifying the project (i.e. statistics/data regarding diabetes prevalence and impact in the AI community); procedures for collecting data (i.e. blood samples for metabolic control, beam-scale for weight, pressure-cuff for blood pressure); risks (e.g. discomfort with finger-prick for blood collection, disclosure or discussion of personal or sensitive information); benefits (i.e. none guaranteed); data confidentiality; voluntary nature of participation; and contact information of investigators and a non-study-affiliated research subjects’ advocate line. Discussions regarding informed consent, related questions, and procurement of signatures on hard-copy consent forms were conducted with each participant individually, and led by project members with appropriate IRB training and credentials.

Data collection was carried out collaboratively, as we recognized that AI community members would be more trusting of these processes if/as other AIs and their families were involved. Additionally, the citizen action group saw the process of collaborative data collection as both honoring the collective orientation of AI people (i.e. this is ‘our’ disease, this is ‘our’ challenge) while at the same time teaching and role-modeling good diabetes self-management skills. Although medical staff supervised these sequences to ensure that data were accurately measured and recorded, AIs and their family members collected each other’s data during every FEDS meeting that was appropriate to collect (e.g. weight), and the providers/researchers collected data that was specialist-specific (e.g. blood samples for A1c assays; blood pressure). AI family community members, providers, and researchers were all present at the FEDS meetings in order to promote and sustain the idea of a partnership and co-creation of health. As each statistical analysis was run by the researchers, and sustain the idea of a partnership and co-creation of AI family community members, providers, and researchers were accurately measured and recorded, AIs and their family members with appropriate IRB training and credentials.

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**Pilot results**

As outlined above, participants in the larger FEDS program include patients with diabetes, their families, and providers. Most patients (and their family members) identify themselves as AI, family members include patients’ spouses, parents, and/or children, and providers represent a variety of disciplines (e.g. family physicians, nurses and nurse educators, dieticians, mental health providers). For the purposes of this pilot investigation, only study participants with type 2 diabetes who identified themselves as AI were included \((n = 36)\). None were taking any type(s) of diabetes-related medication (e.g. insulin). Most of the participants (79%) were female. Mean age was 55 years old, with a range of 22–80. Annual household incomes were distributed across the following range: <$20 000 (68%); $20 001–$30 000 (18%); >$30 000 (15%).

**Measures**

Weight was measured with a standard beam scale at baseline, 3 months, and 6 months follow-up (i.e. at the conclusion of the FEDS series).

Systolic and diastolic blood pressure was measured with an automated Omicron blood pressure cuff at baseline, 3 months, and 6 months follow-up.

Metabolic control (hemoglobin-A1c) was measured with capillary blood samples at baseline, 3 months, and 6 months follow-up. Assays were conducted through a UMN laboratory.

**Statistical analysis**

Data across pre-, mid- (3 months), and post- (6 months) intervention were analyzed using paired \(t\)-tests (see Table 4) to determine mean changes in participants’ outcomes from baseline to 3 months, from 3 to 6 months, and overall change from baseline to 6 months. Analyses were conducted using SPSS/PASW (Statistical Package for the Social Sciences 2009). Pre-post effect sizes (Cohen’s \(d\)) were calculated for matched-pairs data (Rosenthal 1984; Cohen 1988).

**RESULTS**

At 3-month follow-up, participants’ average blood pressure was significantly reduced from baseline across both systolic (139.88–133.18; \(p < 0.05; d = 0.47\)) and diastolic (85.04–78.58; \(p < 0.05, d = 51\)) measures. Metabolic control (A1c) was significantly improved (6.99–6.53; \(p < 0.05, d = 0.45\)). No appreciable change in weight was noted \((p = ns)\). At 6-month follow-up, participants’ average weight loss had significantly improved, from 211.21 pounds at baseline to 196.86 pounds \((p < 0.05; d = 0.53)\). No other measures were significantly improved from the earlier 3-month follow-up data collection. Significant \(p\)-values reported here had moderate effect sizes (Cohen 1988).

**DISCUSSION**

Several strengths of the FEDS project are important to note. First, the initiative employs a wide variety of techniques that
are sensitive to community participants’ perspectives and worldviews, including talking and education circles, opened storytelling, smudging ceremonies, creative arts, dancing, music, and the sharing of community meals and fellowship. The culmination of these activities and methods – tapped through CBPR processes that collaboratively unite A1 community members and western healthcare providers – reflect all members’ respective viewpoints and voices. This is consistent with and contributes to existing (albeit sparse) CBPR literature and practice-recommendations that advocate the re-claiming of traditional ways and integrating them sensitively and purposefully with current scientific knowledge/education en route to better health (Burhanstipanov, Christopher and Schumacher, 2005; Carter et al. 1997; Hood et al. 1997; Davis and Reid 1999; Gilliland et al. 2002; Garwick and Auger 2003; Potvin et al. 2003; Castro et al. 2009; LaVeauz and Christopher 2009; O-Toole et al. 2009).

Second, the FEDS is carried out in the very context(s) that many clinical and AI community members seek to improve (i.e. urban-dwelling AIs who are struggling with diabetes and obesity). Over the course of its evolution and development, AI community- and healthcare provider members in the program defined their concerns and played active roles throughout and across the intervention and research, itself. Solutions to local-level problems were (are) developed and implemented through local-level resources. What was (is) produced is immediately relevant and fine-tuned to the local community; thus, translation of research findings into immediate practice was (is) enhanced. This work extends aforementioned literature through its advancing of knowledge into demographic groups in which most AIs reside (i.e. urban-dwelling contexts), but which have received the least attention across education – and direct intervention – research and care (Urban Indian Health Institute 2004; WhiteEagle 2005).

Finally, by identifying resources (personal and tangible) within the community that were previously untapped, participating members in the FEDS gained an increased sense of ownership in the initiative. They also endeavored (and continue to endeavor) to identify and develop consecutive generations of lay and clinical leaders, with each sequence of the FEDS including both veteran and new leaders/providers. The culmination of these efforts challenges the notion (frequently espoused by academic- and/or health-related fields and literature) that ‘research’ can only be carried out if/when it is first funded by monies secured by professionals and/or that programs/interventions can only be sustained if funded by monies that are secured in such a manner.

Indeed, the FEDS has functioned (and continues to function) with and without external funding. For example, intervention resources (such as food) have at times been provided through the collective contributions of participants, themselves, and at other times through external funding. Professionals’ involvement has sometimes been funded by grant monies; other times it has been advanced through voluntary means and/or viewed as part of ‘outreach’ or ‘community-oriented’ components within existing professional job descriptions. The overall project’s sustainability has thereby been enhanced because it is not dependent on external funding or the charisma and leadership of a single person (e.g. one community elder/leader, one university ‘PI’). Although most existing literature reflects the investigatory efforts of professional researchers who conducted projects that they secured funding to create, advance, and/or evaluate, the FEDS does not function this way. This work supports the notion that both research and intervention/practice efforts can be advanced without depending on (or being delayed by) external funding. In fact, waiting for external funding is conceptually inconsistent with CBPR tenets insofar as to do so would be to rely on professionals’ efforts in grant-writing (which would align with top-down, provider-driven sequences that are incompatible with genuine participatory approaches).

Limitations of the FEDS and its CBPR approach are also important to consider. First, the majority of our participants were women, which reflects a wider literature that has chal-
lenged the healthcare field to better and more effectively engage minority men in its efforts (e.g. Centers for Disease Control and Prevention 2009; National Institutes for Health 2010). As we advance our efforts to do this, future series of the FEDS will work to incorporate activities identified by our citizen action group as more attractive and appealing to AI men (e.g. drumming, field-trips, canoe-building, lacrosse).

Second, although our sample of AI participants closely resembles the tribal membership of the Twin Cities urban population, it is a small sample (n = 36) that was has not been formally evaluated through a randomized-control trial design. Indeed, establishing the effectiveness of a program is generally (or at least preferably) carried out in a manner that includes large samples and a control/comparison group. However, it is our team’s collective sense that a single group repeated-measures design was more appropriate at this point in our CBPR efforts because not allowing some members in the local AI community to participate in an initiative that is otherwise accessible to everyone is inconsistent with the community-oriented (‘we’) nature of AI people.

As we advance our efforts toward a solution to this problem (i.e. how to balance the scientific community’s want for large-scale comparative studies vis-à-vis the local AI community’s want for widespread and welcoming inclusion in a community resource), our team is working to increase and extend the FEDS program locally (i.e. raising project sample size(s)) and to compare its participants through electronically matched comparison groups of more geographically size(s)) and to compare its participants through electronically matched comparison groups of more geographically.

In regard to the replicable or generalizable nature of the FEDS intervention, it is important to remember that CBPR is primarily oriented to producing change in a local community that is comprised of a unique and complex mix of contextual components. Abstract generalizability, once assumed to personify a study’s scientific merit, is de-emphasized in CBPR as other criteria (e.g. the generation of local and usable knowledge) are offered in its place (Minkler 2002; Mendenhall and Doherty 2005). What is (or will be found to be) generalizable, then, may not be the FEDS program in its exact form— but in its participatory process of engaging professionals and community members in partnership to improve the health and lives of AI people who live with diabetes.

To this end (i.e. to honor the scientific community’s high regard for generalizability and local relevancy-to-context via CBPR simultaneously), we are now constructing a FEDS field manual that: (i) outlines the current context of diabetes as an epidemic across AI communities (i.e. summaries existing epidemiological and practice/intervention research literature); (ii) describes CBPR and the Citizen Health Care Model and approach; (ii) summarizes the FEDS and its learnings (including the program’s early history and evolution, collaboration between community members and healthcare providers, process and content of meetings, evaluative methods/findings); and (iv) exemplifies ongoing efforts in sustainability (across resource and leadership foci). Urban areas in the USA with the highest documented populations of AIs include: Anchorage, AK; Tulsa, OK; Oklahoma City, OK; Albuquerque, NM; Green Bay, WI; Tacoma, WA; Minneapolis, MN; Tucson, AZ; Spokane, WA; and Sacramento, CA (Urban Indian Health Institute 2004; Urban Indian Health Commission 2007). AI elders and community leaders across several of these cities have already expressed interest to us in learning more about the FEDS, and their ability to realize efforts in creating similar community-based diabetes programs in partnership with local medical and mental health providers and institutions will be greatly increased through the use of our forthcoming field manual.

**CONCLUSION**

As health professionals and AI communities work together to transcend conventional top-down, service-delivery approaches to care, CBPR is beginning to show promise as a way to partner contemporary biomedical knowledge with the lived-experience, wisdom, and customs of Indigenous people. The FEDS represents such as partnership, as it was collaboratively designed and implemented by local AI elders/leaders in a Midwestern United States community and western providers/researchers affiliated with the University of Minnesota Medical School. Through its integration of traditional practices and ways (e.g. talking circles, ceremonial dancing) with up-to-date knowledge/education about health, and through its targeting of the most vulnerable facets (i.e. urban-dwelling) of AI people, the FEDS has come to represent an empowering resource that neither the AI- nor professional/research- community could have developed on its own.

Participants in the FEDS program have evidenced significant improvement in their health across weight, blood pressure (diastolic and systolic), and metabolic control (A1c) measures. These findings extend existing literature and pre-
vious work that advocates for the careful integration of cultural habits, traditions, and mores into health-related education and interventions (generally), and expands this understanding into the urban-dwelling contexts in which most – and the most vulnerable of – AIs reside (specifically). Future practice and collaborative research endeavors should continue this course, and thereon actively engage/invoke healthcare professionals with community members (however defined) in the creation and implementation of education/outreach endeavors. Further, the FEDS challenges us to do this with or without external funding, as tapping local resources, wisdom, and expertise in communities who are invested in working to improve their members’ health is something that can (and should) rest on the distributed energies of all involved. Programs established this way are likely to be more sustainable over time because they are owned and operated by the communities in which they are positioned, as opposed to functioning on monies secured by professionals, which tend to be temporary and variable.

Future research regarding the FEDS and related efforts must incorporate more effective methods of engaging men. Integrating and including activities recognized to be attractive and appealing to AI males, such as drumming, fieldtrips, canoe-building, and/or lacrosse, is indicated. Further, said research and related efforts must work to address the problem of how to balance the scientific community’s want for large-scale comparative studies vis-à-vis the local community’s want for widespread and welcoming inclusion in a community resource. Comparing intervention participants through electronically matched comparison groups is a promising solution, insofar as patients geographically distant from the intervention (but similar in key demographics) are accessible through integrated medical records systems that are available through practice-based research networks (e.g. Minnesota Academy of Family Physicians, Electronic Primary Care Research Network (nationally)). Additionally, future research in simultaneously honoring the scientific community’s high regard for generalizability with CBPR projects’ want for local relevancy and personalizing of interventions can be rejoined through the construction of field manuals that outline guiding principles and processes of the CBPR work (which can be generalized). As described above, several AI leaders/elders and health providers/researchers positioned in other US urban areas are now posed to do this as they advance local versions of the FEDS program.

Finally, it is worth returning to the greater vision for FEDS: to create a model of health-care, education, and outreach in the AI community as work by and for its citizens, with all stakeholders – including elders/leaders, patients and their families, physicians and other providers – working as active contributors. Everyone involved in the FEDS shows a sense of participating in something of profound significance, and they are energized by this broader vision. At an early meeting when the first author maintained that the FEDS was (is) advancing change in how health is embraced in the local AI community, one of the elders interrupted him and said, ‘This is for all of our people – here in Minnesota and across the country, and even the world.’ As future efforts in FEDS and related CBPR initiatives proceed, this vision of transforming health will serve as a sustainer of energy and commitment in the face of a formidable but inspiring mission.

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