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Abstract

Community-based participatory research has shown great promise as a mutually engaging and respectful way to partner contemporary biomedical knowledge with the lived experience, wisdom, and customs of American Indian people. Designed and implemented through this approach, our Family Education Diabetes Series (FEDS) has evidenced pilot and longitudinal physiological data supporting its effectiveness. However, the multifaceted nature of the program makes it difficult to know which factors are responsible for its success. This difficulty hinders efforts to improve the FEDS and/or inform others' work to advance similar projects. In this study, we conducted a qualitative investigation using talking circles to explore participants' views about what elements of the FEDS are most salient. Our findings suggest that social support and group-oriented sequences hold the most value. We conclude that an emphasis on these processes (instead of program content per se) is most indicated in effecting behavior change and facilitating ongoing disease management.

Keywords

Aboriginal people, North America; community-based programs; diabetes; health care disparities; illness and disease, chronic; obesity / overweight; participatory action research (PAR); research, action; social support

Diabetes is one of the most widespread lifestyle-related diseases in the United States, with prevalence estimates exceeding 7% of the general population (National Heart Lung and Blood Institute [NHLBI], 2004; National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK], 2007). Prevalence rates in the American Indian population are even more alarming, with rates as high as 50% among some tribes. In addition, American Indians experience higher rates of disease-related complications such as heart disease, reduced or lost vision, kidney disease, amputations, and depression compared with White and all other racial/ethnic groups (Indian Health Service [IHS], 2005; Jiang, Roubideaux, Beals, Manson, & Witesell, 2008; NIDDK; Sahnoun, Markland, & Helgerson, 2007; United States Census Bureau, 2010). Few interventions have targeted American Indians, and those doing so have generally focused on those living on reservations. However, up to 70% of American Indians now live in urban areas, and the disparities in health between this group and the general U.S. population are even greater (Rhoades & Buchwald, 2003; Urban Indian Health Institute [UIHI], 2004; WhiteEagle, 2005).

Many providers and communities of patients are now exploring novel and collaborative partnerships that honor and tap resources across both professional and patient groups with a focus on diabetes interventions (Agency for Healthcare Research and Quality [AHRQ], 2004; Department of Health, 2005; Read & Maslin-Prothero, 2011). Community-based participatory research (CBPR) is a promising methodology that emphasizes close collaboration between professional researchers and lay community members (Lewin, 1946; Minkler & Wallerstein, 2003; Wallerstein & Duran, 2010). Hierarchical differences are flattened through a partnership in which

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all participants work together to generate knowledge and solve local problems.

This approach starkly contrasts with American Indians' experience with conventional research (i.e., that conducted by outsiders through top-down, expert-driven methods), which has tended to benefit researchers (e.g., through professional prestige, tenure) more than American Indians, might have pathologized American Indians as dysfunctional, and did not directly inform or advance the communities it was supposed to help (Burhansstipanov, Christopher & Schumacher, 2005; Christopher et al., 2011; Gone, 2006). Emerging projects in American Indian communities support the utility of CBPR efforts in cocreating medically sound programs that are sensitive to local customs and cultural traditions (Castro, O'Toole, Brownson, Plessel, & Schauben, 2009; Garwick & Auger, 2003; Goins, Garroutte, Fox, Geiger, & Manson, 2011; Potvin, Cargo, McComber, Delormier, & Macaulay, 2003). The Family Education Diabetes Series (FEDS) was designed and implemented with a CBPR approach involving local elders and leaders in the American Indian community, as well as health care providers and researchers affiliated with the University of Minnesota Medical School. The program targeted urban-dwelling adult American Indians and their families in Saint Paul and Minneapolis, Minnesota (the Twin Cities), employing a purposeful integration of Western medicine and American Indian cultures.

Community-Based Participatory Research

The concept of CBPR evolved from action research in the 1940s and is characterized by investigations in which academic and professional researchers partner and collaborate with communities to generate knowledge and solve local problems (AHRQ, 2004; Lewin, 1946). Specific approaches vary in the degree to which professionals and community members are involved, and have been described as participatory research, participatory action research, appreciative inquiry, participatory action development, and other terms (Baum, MacDougall, & Smith, 2006; Bell et al., 2004; Heron & Reason, 2001; Ludema, Cooperrider, & Barrett, 2001; Wilson, Ho, & Walsh, 2007). Large national and international health organizations (e.g., AHRQ; National Institutes for Health [NIH], World Health Organization [WHO]) have systematically called for and funded community-driven and collaborative efforts to address complex health and social problems. Community-based participatory research has supplemented action research as an inclusive and characterizing umbrella term (AHRQ; Bogart & Uyeda, 2009; Edwards, Lund, Mitchell, & Anderson, 2008; Pan American Health Organization, 2004).

Community-based participatory research is characterized by several key attributes. Those most commonly recognized and advanced in the professional literature include (a) democratic and equitable partnership between all project members (e.g., participants, community stakeholders, researchers); (b) building on the strengths and resources within the community; (c) a cyclical process in which problems are identified, solutions are developed within the context(s) of the community's existing resources, interventions are implemented, outcomes are evaluated according to what is essential to participants, and interventions are modified as necessary; (d) recognition that CBPR can be a slow and messy process, especially during initial phases of development; and (e) long-term engagement and commitment to the work (Bradbury & Reason, 2003; Doherty, Mendenhall, & Berge, 2010; LaVeau & Christopher, 2009; Mendenhall & Doherty, 2005; Montoya & Kent, 2011; Scharff & Mathews, 2008; Strickland, 2006).

Community-based participatory research has gained credibility in medicine, nursing, public health, and behavioral health since the early 1990s because it can augment cultural awareness, inform understanding of patients' experiences, improve or generate services, facilitate community outreach and engagement, and enhance education (Chavez, Duran, Baker, Avila, & Wallerstein, 2003; Tobin, 2000; Ward & Trigler, 2001). Projects carried out using 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 health care foci (Brugge, Rivera-Carrasco, Zotter, & Leung, 2010; Doherty et al., 2010; Hampshire, Blair, Crown, Avery, & Williams, 1999; Lewis, Sallee, Trumbo, & Janousek, 2010; Lindsey & McGuinness, 1998; Mendenhall & Doherty, 2005; Meyer, 2000; Schulz et al., 2003).

The Family Education Diabetes Series

American Indian elders in the Twin Cities were worried about the increasing prevalence of diabetes and its impact on their people. Alarming, American Indian community members often regarded the disease as inevitable and unpreventable for them. Health care providers working in the community were also concerned about the limited impact of standard medical visits, education sequences, and outreach initiatives. Using CBPR tenets and strategies, we (the authors) and other team members engaged in a new project as stakeholders oriented to a common vision. Over 4 years, American Indian community members sensitized our clinical research team to the

importance of carefully building trust within their community. We learned about American Indian cultures (e.g., Dakota, Ojibwe, Ho-Chunk), spiritualities and belief systems, and habitudes and manners in ways that went far beyond basic textbook knowledge. In turn, American Indian community members learned about Western medicine and gained a better understanding of providers' chief practices and perspectives in care delivery. From this foundation, we worked together to create the FEDS (for a complete account of this process, see Mendenhall et al., 2010).

The FEDS was first launched in 2003. Within the recurring 6-month program, adult patients, their families (spouses, parents, children), and providers (physicians, nurses, dietitians, mental health personnel) were brought together every other week for an evening of fellowship, education, and support. Generally, six to seven providers, four to five tribal elders, and 35 to 40 community members participated. At each meeting, the patients and their families checked and recorded each other's blood sugar, weight, and body mass index (BMI) and conducted foot checks. Participants prepared culturally appropriate meals and ate together. Table discussions focused on the cost and availability of the meals' ingredients, portion sizes, relevance to diabetes, and healthy weight maintenance. The meals were followed by educational sequences that were planned and designed according to participants' interests and wants. These sequences took place within cultural activities such as traditional and modern music and drumming, dancing, American Indian games, aerobics, creative arts, and impromptu theater or role playing.

Instructional topics and program content were similarly diverse and included basic diabetes education; diabetes in the American Indian community; adhering to healthy habits, dietary guidelines, and portion sizes; stress management; fighting depression; exercise and physical activity (outdoors and indoors); obesity and weight control; foot care; wound care; blood glucose monitoring; dental care; retinopathy and eye diseases; kidney health; controlling blood pressure and cholesterol; heart disease and stroke; gastroparesis; neuropathy; diabetes-related emergencies; medical services and supplies; and family relationships and social support. The FEDS evenings concluded with time devoted to informal sharing of experiences and support. These forums were scheduled to last for 3 hours, but most participants arrived early and stayed late.

Anecdotal reports of successful outcomes were common throughout the FEDS. In 2008, we systematically followed participants through an entire program sequence to quantify changes in key diabetes-relevant variables. At 3-month follow-up (midway through the series), participants evidenced significant improvements in metabolic

control (hemoglobin A1c) and blood pressure (systolic and diastolic). At 6-month follow-up, their weight had significantly improved, with an average loss of 14 pounds (Mendenhall et al., 2010). In 2011, we again tracked FEDS participants and found that initial improvements were sustained over time (Mendenhall et al., 2011).

The principal aim of the current study was to qualitatively understand FEDS participants' perceptions about intervention domains and processes that help achieve group success with health improvement goals, and changes that might bring greater success. This is important because the FEDS encompasses complex combinations of educational, social, supportive, and activity-based sequences that appear to be working—but the reasons for success are not clear. Without this understanding it is difficult to improve the FEDS locally or to successfully replicate this work with American Indians in other urban areas that experience similar health disparities.

Methods

Setting and Participants

The Family Education Diabetes Series was held in Saint Paul, Minnesota, at a location that the American Indian community highly regarded as safe and welcoming. The site was operated by American Indian elders and staff and hosted a variety of services (e.g., youth enrichment programs, emergency food services, parenting classes) and public ceremonies/events (e.g., powwows, funerals, fund raisers) oriented to native people. Patient participants in this investigation included 32 adults; 30 identified their primary ethnicity as American Indian, and 26 were women. The participants' ages ranged from 18 to 83 years (mean = 49). All were residents of the Saint Paul–Minneapolis metropolitan area. Twenty-five of the participants had type 2 diabetes; only 2 had type 1. Those without diabetes were identified to be at risk for developing the disease (e.g., secondary to obesity or hypertension). None were being treated at a primary or specialty care facility of any kind (because of lack of availability, uninsured status, and/or cost). None were taking any diabetes-related medications. Annual household incomes were distributed as follows: less than \$20,000, 69%; \$20,001 to \$30,000, 16%; more than \$30,000, 15%.

Data Generation and Analysis

After securing approval through the University of Minnesota's Institutional Review Board, we engaged the FEDS' participants in a conversation (co-led by the authors, who represent both university researchers and community elders) to review the investigation's purpose, highlight questions that would be posed/discussed, and

process questions/answers related to study risks/benefits, voluntary participation, data confidentiality, and plans/uses of findings/conclusions. This was a relatively familiar conversation to the group because they were familiar with the collaborative nature of CBPR and had thereby helped develop the study protocol. With the full consent and understanding of the participants, we conducted six group interviews in the form of talking circles. In American Indian cultures, a talking circle is a highly valued forum in which to equitably and safely discuss important topics (Poupart, Baker & Horse, 2009; Trimble, 2010). Talking circles had already been used in the FEDS to process important program organization and intervention foci (Mendenhall et al., 2010). We limited the size of the talking circles to 6 participants to ensure that everyone had sufficient opportunities to share his or her viewpoints (Kvale & Brinkmann, 2009; Morgan & Spanish, 1984).

We followed a semistructured format to guide the interviews and asked the following questions: What topics did you learn the most from in the FEDS? What parts of FEDS do you find the least helpful? What role does social support play in the FEDS for you? What keeps you coming back to the FEDS? and What ideas do you have for making FEDS even better? Throughout the interviews, we encouraged participants to elaborate and be specific about their opinions and experiences. The nature of the talking circles (which were audio-recorded and transcribed verbatim) meant that the participants and the interviewers jointly produced the data. The interview transcript from each talking circle was treated as a unique data source (as opposed to 32 individual interviews), and each was afforded equal weight.

We organized and facilitated our qualitative analysis of the interview transcripts (documents) through an iterative data reduction method in which information was extracted and orchestrated into patterns, categories, and themes that emerged from the gross data base (Crabtree & Miller, 1999; Creswell, 1994; Kvale, 1997; Pope, Ziebland, & Mays, 2000). The sequence of this method involved the following steps:

1. Get a sense of the whole; read through several of the documents carefully and record initial ideas for categories and themes.
2. Pick one document and peruse it again, recording thoughts about its principal substance.
3. Repeat Step 2 several times with other documents, and then begin a list of all topics and themes identified. Cluster similar topics together. Place these groupings into columns that might be arranged as major, unique, or miscellaneous topics.
4. Revisit the data. Abbreviate topics as codes and record the codes next to the appropriate segments of the text. Modify and add new topics and themes if they emerge.
5. Find the most descriptive wording for topics and turn them into categories. Reduce the total list of categories by grouping topics that relate to each other.
6. Assemble the data belonging to each category and assimilate the categories into a comprehensive picture.

Using this method, we ultimately reached theoretical saturation where data and themes around the questions posed in the interviews began to replicate (Agar, 1996). Following the tenets of data coownership in CBPR (AHRQ, 2004; Mendenhall & Doherty, 2005; Wallerstein & Duran, 2010), we presented our findings to the participants at a later FEDS meeting and discussed the results.

Results

Results were the collective content of the talking circles in this study, that is, the content that was referenced and discussed within every group. Principal themes relate to program topics, the roles of social support, intermember accountability, and next steps for making the FEDS even better.

Program Topics

A wide variety of diabetes-relevant topics were discussed in the FEDS, from basic information about the disease to specific management strategies. When queried about which topics the participants found most useful (i.e., educational), the most common replies highlighted (a) the diversity of topics as a whole, (b) food and diet, (c) exercise, and (d) stress management.

Diversity of topics. Respondents most frequently maintained that no single topic that was introduced, taught, or discussed in the FEDS was paramount. Instead, they appreciated most how all the topics fit together (i.e., the whole was more than the sum of its parts). Several discussed ways in which the dynamic range and sequence of project foci kept them interested (e.g., "Every week is new." "They never say the same things twice!"). They also mentioned factors that made the highly interactive sessions engaging. One man said, for example, that the use of props and impromptu theater to explain the ways that insulin works in the body was "fun" (and educational). Another maintained that the high energy of presenters and group exercises always kept his attention;

a woman in a different talking circle echoed this, adding, “Every time I come, I am learning more and more.” Moreover, participants did not identify any part of FEDS as being the least helpful. One woman remarked, “I haven’t found anything that’s the ‘least’ [helpful]; I’ve enjoyed every one of them.”

Food and diet. The most common single topic identified by participants related to food and diet. Several noted that learning about the components of a “good diet” (in terms of contents, preparation, meal frequencies, portion sizes, and so forth) led them to understand how their current food intake was not healthy. With this insight, participants claimed to have changed their behavior. One woman said she had “learned a lot from these classes, what to eat, and . . . so I quit potatoes, bread. Quit macaroni. Don’t eat any chips. I like popcorn now!” Another participant shared the following experience:

I used to have [candy bars] for breakfast and drink coffee. I did away with that, so now I have bought Special-K cereal. So I have a bowl of that. I did away with my candy bar. My son used to go to the store and say, “Mom, what do you want?” and I would say, “Bring me the giant-sized Snickers,” and that wasn’t good. I don’t even eat eggs anymore. And then I love sausage; I have turkey sausage instead of pork. . . . When I make the bean soup, I get the turkey—smoked turkey. I just love that.

Summarizing her experiences, another woman maintained that the changes she described in her behaviors were connected to changes in her thinking—and that the changes did not mean missing out on enjoyable foods. She reflected, “I have to think different. And you can make it taste good, the dish.”

Participants reported that talking about food and diet led them to consciously read package labels and make purchase decisions based on knowledge gained through the FEDS. One woman explained how her increased ability to interpret labels and understand portion sizes influenced what she bought and what (and how much) she ate:

[I am] reading labels on cans, so that if there’s a lot of sugar, sodium, and so on, I know. And there’s things I really like to eat that I don’t eat anymore. And if I do, I used to get a big bag of chips and now I just get a little bitty bag, and that’s okay. So, I don’t have a whole cup. I have a half a cup. And even the meat has to be four ounces; I have a little scale for it and I don’t eat a whole steak. I’m supposed to eat maybe four, five, six pieces . . . and I eat more vegetables. I got rid of all my canned

foods, ’cause I looked at all of them and they have sodium and preservatives.

These changes were viewed by some participants as not only as essential for improved health, but also as directly connected to survival. One participant shared, “I had to learn all that, and I know that if you take care of your body and you take care of yourself, you live ten years longer. . . . I never thought that I’d see [year] two thousand eleven.”

Exercise. Another commonly identified outcome was how successfully the FEDS worked to engage participants in exercise that was realistic, enjoyable, and sustainable over time. Moderate exercises that could be done anywhere and without expensive equipment or gym facilities (e.g., walking, native dancing, wall push-ups, shoulder presses, bodyweight squats, standing calf raises) were a regular part of the program. These were coupled with discussions about the effects of exercise on blood sugar, the proper use of pedometers, and group activities oriented to exercise (see discussion about social support, below). Exercise appears to have been an engaging feature of the FEDS and was extended to participants’ everyday lives and routines. One man noted, “The exercises that we do, they’re very simple and they’re ones that you can do easily at home and . . . you can even be at work doing some of them.”

Stress management. A common play on words often repeated during the FEDS sessions was “*desserts* is *stressed* spelled backwards.” Put simply, when people are stressed they are more likely to turn to poor choices in diet (e.g., ice cream) than they are to healthy ones (e.g., carrots). Attention to ways that stress, broadly defined, influenced participants’ health was advanced through didactic and group processing sequences about depression and self-care, time management, relaxation exercises, sleep hygiene, and other relevant topics. Specific foci highlighted by participants included depression, stress, getting enough sleep, psychology, and the mind.

One woman reflected on her positive response to a demonstrated stress management technique that compared prioritizing and ordering daily tasks to fitting large rocks (i.e., very important tasks), medium-sized gravel (i.e., moderately important tasks), and sand (i.e., unimportant tasks) sequentially into a jar. Using the jar as a metaphor for either the hours or energy she had in her day, she shared her experience:

Every morning now I get up and ask myself, “What are my rocks?” I have to get out and go for a walk. Exercise is a rock. I have to come here. The FEDS is a rock. Getting the laundry done is like gravel. If I don’t get it done today, it’ll be there . . . tomorrow. Watching TV? Being lazy on the couch? That’s

sand. I can do that after I've made sure that I've taken that walk. Then it can be a reward!

Another participant explained how adhering to strategies of sleep hygiene helped him sleep better, feel less depressed, and be more motivated to engage in daily diabetes management. He said,

Well, after I heard it about thousand times in here, I finally moved my TV out of the bedroom. And when I can't sleep, I get out of bed and go read instead of tossing and turning all night. There were some days that I was just so tired! But now I am sleeping better, and everything's better.

The Role(s) of Social Support

Much of the objective information that participants learned in the FEDS could have been gained through visits with a physician, or through an Internet or library search. However, the FEDS program relayed its content in an overtly social manner. Unlike a conventional primary care clinic where patients are seen individually with little social interaction, FEDS served as a forum where participants' well-being and disease management efforts were framed collectively.

Participants in the FEDS described each other as a community of men and women who cared about each other's health (i.e., not just their own). This reciprocal and mutual concern was based on a sense of friendship and enjoying others' company (e.g., one woman noted, "We've met wonderful people at the FEDS!") within the context and experience of fighting a common disease. One man explained, "It's the camaraderie. . . . We have the same problems. . . . Each one of us has diabetes, [so we are] learning together how we're supposed to take care of ourselves." A woman said that the most important thing to her in the FEDS was "the fellowship. . . . We are trying to help each other out just by being here, you know. We all share. We all have something in common. You're not alone. You don't feel alone." Another explained that

[e]verybody's in the same boat, and I think the people here are just so nice and helpful and non-judgmental regarding any of the results, whether you've lost or gained weight or anything. Everybody here that's participating suffers from the same disease and everybody's goal is to make that suffering the least or that it does the least harm to you.

A mother participating in the FEDS with her son communicated a similar sentiment, speaking about the

wisdom of having adolescents talk with adolescents (vs. engaging in power struggles with adults):

[The FEDS is] a community thing. [Diabetes] affects all of us, men and women. My son's here, sitting over there. He drinks pop, and I tell him the dangers of pop. All that sugar and . . . he'll listen to somebody else, or by being a part of this he'll understand how it's not just me talking and telling him what to do.

Several participants commented that they checked in on, reminded, and supported each other outside of the FEDS meetings. One woman explained that "if somebody from the group's not here, we wonder what's going on . . . if they're okay, [so we] check up on each other." Conversing with a man in her talking circle, another woman said, "You remind her, she reminds me, and otherwise we sometimes forget. We're old and we forget lots of things." From telephone calls with meeting reminders to sharing recipes or going for walks together, members of the FEDS appeared to watch out for each other's well-being while attending to their own.

Intermember Accountability

FEDS members also described a sense of intermember accountability and shared effort toward health-related goals. Making a public declaration to change behavior (e.g., to exercise, to stop smoking, to live a sober life) was seen as a more powerful motivator than silent personal affirmations. FEDS participants maintained that their comradeship was a principal driver for communal efforts.

Commitment to the group. The FEDS was an open community-based forum. It did not screen applications for membership or require agreements for participation. However, new participants, welcomed warmly by veterans, often experienced a powerful draw to the group's efforts with improving health. One noted, "I had to come here. When you make a commitment, that's part of the commitment to make yourself healthier." Another described the reciprocal nature of this process:

Yes, [I feel accountable] because we're all trying to do the same thing. . . . We are trying to show each other that we can do it. . . . [We're] getting together and showing each other that we can do this.

Collective data. Participants in the FEDS were good (or became good) record keepers. They were encouraged to systematically track physical data (e.g., blood pressure, blood sugar, weight, BMI), dietary intake (e.g., food diaries, label reading), and exercise (e.g., minutes,

steps, miles). Although this enabled individuals to watch (and be motivated by) positive changes in their data, respondents strongly emphasized that the process of aggregating data served to motivate healthier behaviors. Common FEDS sequences involved participants working as a team to accomplish a group goal or to compete with subgroups situated within the overall program.

This connected individual efforts to manage and report health to the larger group, and thus compelled all involved to work even harder. One woman reflected that, on her own, she would likely not be vigilant about recording her weight, “but here we write it down, and I got a computer. And [name] was on [email], reminding us . . . and so I said I gotta go [exercise].” Another woman said, “Here I keep my journal and I’m starting to see my weight and see my blood pressure [change], so that’s encouraging . . . when doing it at home on my own, it wasn’t working.” Still another woman shared that she liked

the whole pedometer thing and the steps and the trying to be part of the group and . . . everyone’s excited . . . people going over the exercises. Like sometimes we see [name] on the weekends, and again just seeing her triggers that, “Oh yeah, I should be doing this!” or “Hey, I did this!” and [it] makes me feel better.

Collective goals. Many of the group initiatives advanced by the FEDS involved team players working toward a larger goal. For example, members decided to collectively walk the equivalent of the latitudinal distance of the continental United States (i.e., from the west coast to the east coast) and to do this as two separate teams in a friendly competition for the fastest time. This required all FEDS members to record their steps with a pedometer and add up their respective distances at each meeting. This was found to be an engaging way to extend attention to exercise outside meetings and to reinforce individual contributions to collective goals. One woman remarked, “So we were walking across the United States. I thought [we’d] better beat ’um!” Another said that she was “trying to be part of the group and everything and support everyone else in their steps.” She went on to share the following:

Before, I didn’t really put my exercising towards anything as a group, and I found that it can add to our steps and add to our totals. . . . [It] makes me feel better about what I’m doing, not only about myself, but as a [part of the] group.

Next Steps: Making the FEDS Even Better

Participants’ principal suggestions for improving FEDS centered on increasing group and social activities.

Social activities for exercise. Suggested activities related to physical exercise included drumming groups, round dancing, charity walks, and relaxation and yoga. For example, one participant noted, “One time we did do some native dancing, like what you would do at a pow-wow, and it was really fun. And you could really feel that you were exercising.” He went on to say that “there’s walks for juvenile diabetes and walks for MS [multiple sclerosis]. . . . It would be fun if we knew about those and anybody that was available to do them.”

Social activities for healthy eating. Suggested activities related to healthy eating included learning how to garden (e.g., grow vegetables and herbs indoors and outdoors) and sharing/cooking new diabetes-friendly (and good-tasting) recipes. One woman shared the following:

I know how to throw things in a pot or a pan, but I don’t know how to season foods to make them taste marvelous like this [referring to food being shared in talking circle] with a lot of seasoning. I never would have thought of it!

Other suggestions were to work together to make 100-calorie snack bags and learn how to barbecue healthy foods during the summer months.

Discussion

The topics introduced in the FEDS were extensive, and participants struggled to identify any one as most informative or helpful. This was not surprising, given the diverse and collaborative nature of program elements and that the FEDS comprised equal contributions from academic and community partners. The academic researchers and health care providers emphasized the biopsychosocial nature of health (Engel, 1977, 1980; Fava & Sonino, 2008), and the American Indian leaders and elders emphasized traditional understandings of balance through Medicine Wheel models of health (Kattelman, Conti, & Ren, 2009; Trimble, 2010). Most program emphases were placed on improving health and sustaining beneficial changes with respect to diabetes management through multiple foci (e.g., diet, exercise, stress management). This was consistent with literature showing that emphasis on one topic with less attention on others (e.g., eating well, but not exercising) is unlikely to achieve success (American Diabetes Association, 2011; Gomersall, Madill, & Summers, 2011; Lipworth, Hooker, & Carter, 2011; Maxwell & Cole, 2009; Minet, Lonvig, Henriksen, & Wagner, 2011).

Another reason for the participants’ difficulty in selecting any single topic as the best might be that the actual topics presented were less important than the engaging experience of participating in the program

itself. If recording and tracking health-related data are fun, visual, and part of a collective effort, these activities can be an engaging and appealing process. The fact that diet and exercise, as individual topics, were most frequently singled out (when topics were singled out) supports this notion, because much of the FEDS' participatory pedagogy attended to these areas socially—for example, discussing and sharing meals together, reading and processing information from food labels as a group, exercising and dancing together, advancing group contests that encompassed physical activity.

It is important to note that the value of social support in achieving positive health outcomes was the dominant theme in all of the talking circles observed in this study. Program participants knew that they were gathering as a community of people who cared deeply about each other's health and that they were managing a common disease. As relationships evolved through multiple meetings, a sense of camaraderie and collective solidarity emerged and participants supported each other's efforts in making necessary changes in their behaviors. They began to feel accountable to each other to honor personal and group commitments.

More specifically, participants identified and pursued collective goals involving all members (e.g., walking the equivalent distance of the United States' latitudinal width). When asked about what kept them coming back to the FEDS, participants identified social activities. When asked how the program could be further improved, participants emphasized a desire for more social activities, group goal setting, and community-centered learning. There was less interest in more services that professionals could provide or new educational topics. It was clear that attention to facilitating spaces and processes for people to connect with one other around key content areas of disease management was an essential element to program success.

Conclusions

The FEDS program is the product of collaborative efforts between university community members and urban American Indian community members to create something that neither group could have developed on its own. Tapping local community resources that were previously untapped served to engage local American Indians and their families who were living with diabetes to unite in a collective and engaging mission toward health improvement. Using professional expertise selectively (i.e., “on tap, not on top”) and integrating it into the evolving social fabric of the FEDS served to promote group efforts toward positive behavior changes that beneficially influenced health and functioning. Quantitative pilot and longitudinal data have shown that the program was

successful (Mendenhall et al., 2010, 2011). The qualitative data reported here indicate that the social and group-supporting activities are the most important elements of that success. Ensuring adequate and welcoming space for these activities is a critical component of achieving positive individual and group experiences.

American Indian leaders/elders and health providers/researchers in other urban areas can use the results of this study to create local versions of the FEDS program. Their work can be expected to advance CBPR principles and fulfill the need of local communities for immediate and personally relevant interventions that combine community wisdom with contemporary medical knowledge about disease processes and effective management. Harnessing the power of the collective with groups working together in a welcoming social and supportive environment is fundamental in the construction of something that is owned and operated by its members.

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