



The East Metro American Indian Diabetes Initiative: Engaging Indigenous Men in Reclaiming Health and Spirituality through Community-Based Participatory Research

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Abstract

Diabetes affects American Indian people at higher rates than the general US population; within this community gender disparities overwhelmingly affect men's health. Using Community-based participatory research (CBPR) and talking circles we asked AI male participants to share their perspectives about which culturally inclusive features of the program serve to best engage them and contribute to improved health (e.g., purposefully integrating sacred cultural and spiritual activities, reclaiming roles as strong and valued family men, and giving support appear to facilitate behavior change and health/disease management). Future directions and implications for partnership with AI communities are offered.

Keywords: Aboriginal people; North America; Community-based programs; Diabetes; Health care disparities; Illness and disease, Chronic; Obesity/Overweight; Participatory action research (PAR); Research action

Introduction

Diabetes is one of the most widespread lifestyle-related diseases in the United States, with prevalence estimates exceeding 7% of the general population [1,2]. Prevalence rates in American Indian (AI) people are even more alarming, with rates as high as 50% among some cohorts and tribes. Further, AIs experience higher rates of disease-related complications like kidney and heart disease, reduced or lost vision, amputations, and depression compared with other racial and ethnic groups [2-6].

Within this larger frame of health disparities by race and ethnicity, marked differences by gender also give cause for concern. The National Institutes for Health [7] has called attention to longstanding, research that documents males' comparatively poor health and life expectancy compared to their female counterparts. Across a host of health indicators (e.g., weight, blood pressure), disease statuses (e.g., diabetes, hypertension, Alzheimer's disease), and health-related behaviors (e.g., cigarette smoking, physical activity), men tend to fare worse than women. Further exacerbating these differences is the fact that men (of all races/ethnicities) seek health care services less frequently than women, delay the onset of seeking services more when they do (resulting in comparatively severe and/or developed clinical presentations with poorer prognoses), and participate less in educational or healthcare outreach initiatives designed to improve health.

Many providers and communities of patients are now exploring novel and collaborative partnerships that honor and tap resources across professional and patient-groups that focus on preventing diabetes and/or improving its management [8-10]. Community-based

participatory research (CBPR) is a promising methodology that emphasizes such collaborations [11-13]. Within these partnerships, hierarchical differences are flattened and all participants work together to generate new knowledge and solve problems that nobody has addressed effectively yet. Emerging projects in AI communities support the utility of CBPR efforts in co-creating medically sound programs that are sensitive to local customs and cultural traditions [14-18].

Community-Based Participatory Research

Community-based participatory research is characterized by investigations in which academic and professional researchers partner and collaborate with communities to generate knowledge and solve local problems [8,19]. Within this larger frame, guiding tenets include: (a) equitable and democratic partnerships between all project members (e.g., researchers, patients/participants, community leaders and stakeholders); (b) building on the resources and strengths within the community, itself (versus working to secure outside funding before creating/advancing anything new); (c) cyclical processes in which problems are identified, solutions are developed, interventions are implemented, outcomes are evaluated, and interventions are modified as necessary; (d) recognition that CBPR is often slow and messy, especially during initial phases of development; and e) long-term engagement and commitment to the work [14,20-25].

The East Metro Diabetes Initiative (EMDI) Men's Group

American Indian elders in the Twin Cities (affiliated with the St. Paul Area Council of Churches' Department of Indian Work) were worried about the increasing prevalence of diabetes and its impact on their people. Alarming, 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) engaged in a new project as stakeholders oriented to a common vision. American Indian community members sensitized the clinical research team to the importance of carefully building trust within their community and learned about AI cultures (e.g., Dakota, Ojibwe, Ho-Chunk), spirituality and belief systems, and habits and manners in ways that went far beyond basic knowledge. In turn, AI 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 Family Education Diabetes Series (FEDS) [14].

As the FEDS evolved and gained stability in the local AI community as an active form of education and support dedicated to the health and well-being of AI people through traditional teachings, values, and cultures, external monies were secured to formally evaluate its effectiveness. While an increase in positive outcomes were observed in participants' health over time (e.g., metabolic control, weight, and blood pressure), we also documented and confirmed what was already anecdotally known: the vast majority of those participating were women. Leaders and community members had been trying for some time to get men to participate, but they rarely did.

The East Metro American Indian Diabetes Initiative (EMAIDI) was created through a State-funded mechanism (e.g., Eliminating Health Disparities Initiative) in an effort to better engage AI men. One of the authors took the initiative with this effort by meeting with four local elders and spiritual leaders for guidance, who advised that the best way to begin engaging men would be through reconnecting their sense of spirituality. As he met with members of the community he spoke to them about spirituality and putting community members on a "path" and a "way of life" that is grounded in wisdom, knowledge, and behaviors oriented to life-balance and good health. After hosting a feast for men in the community, this author led the formation of an action group, consisting of 16 men. As this action-and-planning group met (several times), a sense of brotherhood emerged wherein men wanted to reconnect and benefit other men who had lost their "way" as fathers, brothers, sons, and husbands to their families. They worked to hold more feasts and ceremonies as a mechanism to recruit, and began each meeting with prayers and smudging to maintain tradition. They also began attending FEDS meetings to bridge community efforts.

Methods

The principal aim of the study described here was to conduct a qualitative investigation into our current work of FEDS with the EMAIDI Men's Group. We used an iterative methodology based on grounded theory [26] which is a qualitative methodology well suited to explorations of perceptions and meaning-making. Perceptions and meaning making are important to understand within this context because the men's group encompasses complex combinations of spiritual- (e.g., prayer, drumming), educational-(e.g., small-and large-group forums), social-(both formal and informal), supportive-(e.g., 1:1 exchanges, talking circles), and physical sequences (e.g., dancing, wood-cutting, canoe-building) that appear to be working, but without a clear sense of why. This makes efforts to improve the group and replicate our work in other urban areas that shoulder similar health disparities with AIs difficult.

Setting and Participants

The FEDS is held at the St. Paul Area Council of Churches in its Department of Indian Work in St. Paul, MN. This site is highly regarded by the Twin Cities AI community as a safe and welcoming place, as it is entirely operated by AI elders and staff and hosts a variety of services (e.g., youth enrichment programs, emergency food services, parenting classes) and public ceremonies/events (e.g., pow wows, funerals, fund-raisers) oriented to Native people. Participants generally include between 20-30 AIs who reside in the Minneapolis/St. Paul metropolitan area and are either diagnosed with diabetes or at-risk for developing the disease (e.g., secondary to obesity or hypertension). Those participating in the current study included the leaders of the EMAIDI Men's Group, who also participate in and are representative of a sub-set of this larger FEDS group; the men who participated in the talking circle included 9 AI males (representing various tribes, ages 28-65).

Data Generation and Analysis

After securing approval through the University of Minnesota's Institutional Review Board, we conducted a talking circle, a forum which many AI cultures utilize to equitably and safely discuss important topics [27,28]. The limited size of the talking circle conducted here ensured that everyone had sufficient opportunities to share their viewpoints [29,30].

We followed a semi-structured format to guide the interviews and asked the following questions: *What parts of the group do you find the most/least helpful? What topics have you learned the most from? What role does social support play for you? What keeps you coming back? What ideas do you have for making the group even better?* Throughout the interviews, we encouraged participants to elaborate and be specific about their opinions and experiences. The nature of the talking circle (audio-recorded and transcribed verbatim) meant that the participants and the interviewers jointly produced the data. We organized and facilitated our qualitative analysis of the interview transcript 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 [31-34].

The sequence of this method involved the following steps: 1) Get a sense of the whole; read through the document carefully and record initial ideas for categories and themes; 2) Peruse the document again, recording thoughts about its principal substance; 3) Repeat Step 2 several times, 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.; 6) Assemble the data belonging to each category and assimilate the categories into a comprehensive picture.

Four of the authors conducted initial separate coding (Steps 1-3); the findings that emerged from this process were then sorted into themes. We eventually reached thematic saturation, wherein data and themes around interview questions began to replicate [35]. Following the tenets of data co-ownership in CBPR [8,13,22] we presented our findings to the participants at a later FEDS meeting and discussed the results.

Results

Results reflect the collective content of the men's talking circle in this study. Principal themes relate to information and knowledge about program topics, sense of personal and collective pride and dignity, strength in being together as men, and behavior change.

Information and knowledge about program topics

Information and knowledge proved to be the first step for many of the men in the group and an important factor in creating an environment facilitative for behavioral change. Many of the men pointed to the wide variety of topics pertaining to food/diet, exercise, general diabetes care, and disease-related information that was presented in the FEDS as being very helpful to their efforts to control their diabetes. As one AI man explained, "For me, it's the information for the diabetes cause I'm borderline diabetic and [there were] a lot of things I didn't know about, didn't have no clue about."

Food/Diet: One of the most frequent topics that participants mentioned as being useful was food/diet. At FEDS, a meal is prepared for the group that is healthy, diabetes-conscious, low in fat and sodium, easy to prepare and low in price. Many of the participants commented on the importance of this learning. One AI man said, "I like the food that we've been making and [how it is] showing that you can make good food, healthy food." Another commented, "I like all the healthy meals that [we have] been making and all the different types of healthy meals that we've had and I've learned a lot just by listening."

Two men commented that their grocery shopping has changed since learning more about healthy foods and diets. This learning flows throughout the family system. For example, a man mentioned that he is now "watching how my family eats . . . learning more healthy ways to eat." Another is "shopping for healthier foods [that are] low salt [and] sugar free" and another is trying to consume "less sugar and salt."

Exercise: A second area of knowledge that participants pointed out as being a catalyst in their pursuit of a healthier lifestyle was exercise. Simple exercises that can be easily incorporated into everyday life were reported to be the most useful. A popular resource that was offered was a video explaining the great health benefits of 30 minutes of daily walking. This turned out to be a favorite for one AI man who commented, "Most of all I like the video we watched and how it talks about how much walking helps your life and what it does for your life and just all the information involved-I enjoy it all."

The majority of the men spoke of incorporating different types of exercises into their daily routines. Learning how much exercise affects long-term health and good diabetes outcomes seemed to be crucial in spurring these participants into incorporating physical activities into their daily life.

Diabetes information: Learning about the basics of diabetes was identified as having helped to inform participants about the exact nature of diabetes and the benefits of actively fighting for a healthy lifestyle. Many have discovered that they do not just have to sit back and wait for diabetes to come; they can engage in a healthy lifestyle in hopes of preventing it; one AI man said, "Learning about diabetes prevention has helped a lot. It runs in my family, but it doesn't have to".

Personal pride and dignity

Realizing an increase in sense of hope. Several men reported espousing the belief that acquiring diabetes was an unavoidable reality,

and that they therefore did not possess hope for a better future. Through this program, however, many have come to understand that the disease is preventable and manageable. There appears to be a deeper understanding that they, themselves, can make a difference; they are not destined for a future with the disease and/or a future of uncontrolled disease management. As one man pointed out, they now see different types of eating and ways to keep healthy instead of all the bad things, like drinking and drugs and abuse; it's just a good thing for sober people and people on the right path in their lives to come together and share their experiences and I [now] wouldn't change a thing.

This man stated, like others, that he has begun to experience positive changes and that he can see the effects these changes are having on his life. Another participant shared how he now has "positive thoughts [and] feels happy." Yet another man stated that he now has more "positive surroundings." These men are internalizing this sense of positivity and hope around diabetes through their experiences with the group.

Sense of belonging: Many of the men noted the importance of believing that they belong to something. One AI man commented, "I think that a group session is a lot better than individual because . . . the ideas that will come forth from a group are a lot more helpful." This man reports that he is learning more because of what the other men in his group offer him and the perspectives that they bring to the larger forum. This group, another man remarked, "brings everybody together." It is a place where men can come and just "be" - a place to connect. The bond that these men have forged is displayed quite clearly by one member as he explains that, "We use the tools that we've learned here and togetherness, we've stayed together and we'll just continue to keep coming." Benefits of being part of this larger community seem clear to them.

Sense of giving back: Through participating in the men's group, many of the participants report that they have strengthened their resolve to give back to their people and contribute to the community. As one AI man said:

When we first started coming here it felt like just something that we're gonna go do and now it feels like something that it's good to do-we get to come here and doing for other people and hopefully lift their spirits a little bit, yeah it's been good.

Another man had similar thoughts, "I would just like to say that it's good that the men's group is coming here to FEDS because there's definitely a large part of the education piece that's being shared and appreciated." He realizes the contribution that he is making to FEDS just by coming. Another man explained his journey in the following way:

I never thought I would volunteer my time before this group but it's been a good experience . . . In the last six months I have done more within the community than the first 29.5 years of my life and it feels good to meet new people . . . Just to hear 'thank you guys' made us proud and them words mean more than money.

These men have begun, as one commented, "helping in the community any way possible."

Collective pride and dignity

These men report they are experiencing a newfound sense of personal pride and dignity for the group, and along the way they are

beginning to think similarly about their collective group identities (whether it is as an AI man, a father, or a son).

Men coming together: Participants shared how when men can come together as men, a deep and rich community can be created with bonds that run deep. Several men offered their perspectives of this process which include having the opportunity of “helping elders with anything we as men can do” and becoming “interested in being part of the men’s group – a helping dad or husband.” These men are also embracing their leadership in terms of seeing the important roles that they have within their community, especially in terms of role modeling for the youth:

I had my last drink early December and it’s been a lot easier than I thought having all my brothers around to support me. I’ve been going to sweat [lodges] ever since I joined the group and the teachings have been very helpful. All the small things added up and helped me realize that we need Native men who don’t drink so the children have some positive people in their lives.

Another man shared, “I’d say that we’re all pretty much grateful as a whole for the things we’ve learned here; being able to share them together – it’s been helpful.” These men are doing the work to claim their identity as AI men and to assume all of the responsibility and benefit that this entails.

Supporting family: Many participants have commented on the family time that the weekly FEDS meetings create for them. For example, one member stated, “It’s a good time-[to] come out here to have a good time and see all my relatives together again and all the people just coming together and having a good time, having some laughs.” Another said, “I like being able to come here and get a good meal and just being able to take my family all together and meet with new people. It’s good.” Not only are they getting to spend time with family members in a public space, but another of the men also reports “spending time with my son and granddaughter” outside of the FEDS meetings and that they are, as a family “getting more involved in our traditional way of life.”

A family within this culture is not only the biological family, but also the community itself. As one AI man explained:

A word that comes to my mind is a word that was originally used when the men’s group came together and started doing things together and the way we, it was shared, it’s a Lakota word . . . they said “*Tee-osh-pah*” and . . . that’s like a family, and a family way, and so with that being said, then, being missed and being here and coming back to me is-like my brother to my right once said – “I feel responsible because we have a way,” we have something that we’re trying to do and give back to the people and be a part of that sharing is very important and it feels good.

These men report having created a sense of brotherhood within the men’s group while also collectively becoming more active participators and members within their own families.

Deepening culture and spirituality: Culture and spirituality are important aspects of this men’s group. One purpose of their coming together is to connect and celebrate it. This emphasis on being culturally congruent is woven throughout the FEDS program. These men bring a variety of culturally and spiritually foundational practices into their work, with very positive results. One man said:

Keep it simple and, you know, the spirit moves. The drum is here, the singers are here. We keep coming back and it’s a very good start

‘cause more things will develop from that in terms of activities that would prevent diabetes. We’ve got the song; now the dance can come in and other things that come along with that and, however you want to incorporate that into . . . FEDS program.

Another man felt similarly: Native people, we have a way and so I’ve noticed that we have prayer and then we sing and then we eat . . . But that’s the way, that’s what binds everybody together and makes the circle complete and I think it’s in a good way, you know. It helps everybody to feel good about whom they are. That identity piece is there. Everybody from the community – from the babies to the elders and everybody in between – are participating together and it’s the education piece and with the drum here and everybody together that’s our heartbeat and so it just, it really solidifies the whole program on a spiritual level.

With pride in their culture and spirituality taking a center role in their lives, many of these men are becoming more deeply involved in AI ways of life. Many are participating in singing and drumming, attending and helping out with traditional ceremonies, and learning more about their original traditions and habitudes. An AI man said very simply, “I would just like to say thank you – on behalf of our group – and letting us use this time to also come together, sing our music, give place to our drum, and our people and help each other learn.”

Supporting one another: Participants shared how they have learned through their experiences how valuable social support is in reclaiming their health and identities. While it is difficult to make life changes on one’s own, through affirmation, encouragement, compassion, caution, and humor, these men have bonded together for their common (and individual) good.

Getting affirmation: Receiving positive attention and validation from others for making difficult changes can go a long way for these men. Participants reported receiving support in two principal ways: via group interaction and by people noticing positive changes from the outside. One AI man conveyed that talking together in group affirmed what he was doing and gave him the strength and support to continue:

When you have a group of people, they learn more because . . . they can talk more about . . . what they’re experiencing and maybe you haven’t heard it yourself and when somebody say something it reminds you.

While discussing the value of outside affirmation, one man explained that, “My uncle, born and raised in the Twin Cities, drinks and does drugs, but when he told me he was proud of what we were doing it really made me cry. Its things like that that makes it all worthwhile.” These men have felt the power that the affirmation of their community can have on supporting important behavioral changes.

Giving and receiving encouragement: The AI men within this group have become and continue to be a source of encouragement for each other. The support that they receive from one another to keep pushing forward toward a healthier lifestyle and connecting to their AI roots is a strong factor in keeping them committed. One AI man said that since we are a group and we support each other, and we do miss each other when we’re not . . . present. If somebody’s sick we try to contact them to see how they’re doing, you know, because we are a support group within ourselves and I think that that helps us all a lot. If I’m feeling down, I might call one of them to help lift myself up and they help me lift up.

They have created a support network and will continue to thrive because of it. They utilize each other and rely on the encouragement and support of one another to maintain the changes that they are making.

Having compassion: The care and support that these men experience have turned outward to the AI community at large. This group of men has become a staple at the FEDS meetings, faithfully coming to every meeting and bringing their drums to play and to sing by. Two men spoke of their commitment to coming. The first stated that:

I believe I would feel like I had missed something, not being around the guys in the group, my group, my circle, and we were asked to come here and be part of this and we make sure that we're here.

The second man reiterated that "now it feels like something that it's good to do we get to come here and sing for other people and hopefully lift their spirits a little bit. Yeah, it's been good."

Holding each other accountable: While striving to make healthy changes in their lives, changes that pertain to healthier eating, exercising, and general diabetes management, many of these men are also coming together to kick old habits and holding each other accountable. This support is incredibly important, as one AI man states, "I might call one of them to help lift myself up and they help me lift up. So . . . if I'm thinking of going after a little bit of drinking then they might help me not to do that." It is of great importance to these men that their friends hold them accountable for not returning to old bad habits and help support them so that they can continue the positive behavioral change.

Using humor: One finding we came across during the talking circle was the way the men use humor and banter while discussing important topics. Humor in this case could be a way of mediating or minimizing the vulnerability inherent in these conversations. This levity showed itself at first with a running joke among the men as they passed the recorder (or "talking stick") around the circle as each member of the talking circle added their thoughts. Early on in the talking circle as it became clear that there was agreement between the members; one man said "I agree with the gentleman to my left." Subsequent agreements were voiced in a similar manner and then the comedy stakes were raised in the following way:

First participant: I agree with the gentleman to my left . . . I enjoy getting the fun food facts [and] the meals that are coming in 'because they're all delicious.

Second participant: Also I agree with everything, maybe some time for us coming you can try to sneak us some Debbie snacks (a snack cake) [NOTE: This is a tease that is directed at the PI and the program in general; Lil Debbie Snack Cakes are a junk food staple in many parts of the Midwest.]

Third participant: I agree with that guy right there, I say everything he says (at this there is a huge burst of laughter from the group)

Later on in the interview this same one-two-three punch came up again when participants were asked about what keeps them coming back to the FEDS. Given the fact that they each received a gift card for participating in the qualitative research interviews that were conducted that particular night, they seized on this as yet another way to tease the PI (who was also sitting in this particular talking circle as a facilitator) in this manner:

Question: What keeps you coming back to FEDS?

Man 1: Gift cards (laughter)

Man 2: Singin' for gift cards (more laughter)

Man 3: Singin' for a meal! (Even more laughter from the group)

Humor and giving each other a hard time has long been an acceptable way of bonding among men (Romero & Cruthirds, 2006) and it seems to be the case here that these men are teasing each other and the PI about the truth of what is going on with them in this group. After having been quite honest and open about many of the reasons that they like the FEDS and have benefited from it, they show how at ease they are feeling with one another by beginning to make jokes about the program and then try to top each other as they go (the one-two-three pattern that is presented above, which is a classic comedic template in the joke, a topper and then a final topper.)

Behavioral change: As each participant in the men's group becomes more equipped with information and knowledge, the natural result appears to be significant behavioral change. One man commented that, "Everyone can see, hear, feel, smell and taste the difference." This comment points out the holistic nature of the type of behavior changes that are being achieved in these instances.

A large part of leading a healthy lifestyle is eating healthful foods. Food and diet is a topic covered in the FEDS, the growing knowledge of which has translated into changes made in the lives of many of these men. The awareness of which foods are or are not good for your body has produced change, as one AI man pointed out, "I am changing by being more aware of the things that I put into my body – being more conscious of things that are harmful and helpful." Also, many of the men said they are now cooking at home more frequently and changing their grocery shopping behaviors. "I never gave it much thought but there has been a shift from eating fast food at least twice a week to not eating any fast food. When I do the shopping I get plenty of fruits and vegetables." Others have worked on incorporating their new healthy eating behaviors into their family life, "In many ways we try to eat healthy and eat together. Some of my uncles, brothers, nieces and nephews are watching and they see how well we are doing." The changes that a majority of the men have put into place include consuming less sugar and salt, and eating more vegetables and wild rice. The men are also turning less frequently to fast food as an acceptable meal option.

Another behavioral change that many of the participants discussed is having integrated exercise into their lives. One topic covered in the FEDS regarded the importance of walking: the fact that just walking 30 minutes every day is an easy way to become more active. Four men explicitly stated that they now walk every day. Others have become involved in a softball league to exercise and interact socially with others. By way of getting more involved in the AI community, men have become more active. They volunteer their time shoveling snow, gathering wood for the lodge, and drumming.

Discussion

The themes presented here point to the importance of collective- and social- support in efforts to change behaviors related to health. For academics, the incorporation of social considerations with physical and mental health is a relatively recent discussion that was initiated with the introduction of biopsychosocial theory [36]. However, combinations of these concepts have been evident in many AI traditions for centuries. For example, the Medicine Wheel model

[28,37] integrates mental, physical, spiritual, and social ways of life to emphasize understandings about and the sacredness of life balance.

The Medicine Wheel, which aligns with notions of balance in directions (North West, South, East), colors (white, red, black, yellow), dietary components (four legged animal, water, trade crops, gathered crops), seasons (winter, fall, summer, spring), life stages (elders, parents, youth, children), elements (wind, water, earth, fire), and so forth [37]. While different tribes have slightly different interpretations of the wheel, each focuses on balance between each portion of the whole. Balance is seen as a process, and something that is learned and maintained through time, rather than something that is achieved.

Among AI patients with diabetes, social support (balanced with individual accountability and actions) correlates highly with checking blood glucose and logging on to web-based systems to communicate with health professionals about diabetes [38]. Social contexts are also important for AI men recovering from alcoholism [39]. While the participants described in the current investigation were not all recovering from alcoholism, one man discussed “losing using behavior” (referring to alcohol) and another said it was a “good thing for us sober people . . . to come together and share [our] experiences.” These comments highlighted their desires to keep each other accountable and continue to make healthy living choices. Both of these findings of seeking out medical care and sustaining healthy choices highlight the importance of social support. For the participants, the support they gave each other has meant improving diet and exercise alongside resisting host of unhealthy behaviors.

In addition to explicitly discussing social interactions and relationships as supportive, the mood of the talking circle was also indicative of such. The use of humor and banter between group members and with the facilitator can be perceived as positively pro-social; the interactions are representative of close relationships. Positive humor styles have been found to be positively correlated with social competence and the ability to manage emotions [40]. The use of humor within a group has been shown to positively affect relationships; for instance, fraternity brothers who teased each other rated each more favorably than those not included in the teasing [41]. This finding indicates that using humor within a group can strengthen relationships by increasing feelings of kinship and favorability. Further, the use of humor is associated with increased pleasure and confidence in social interactions [42] and can enhance group cohesiveness, communication, and organizational culture [43].

Perhaps the most encouraging outcome reported by participants is their newfound sense of hope and perseverance vis-à-vis a chronic illness that once was perceived as unavoidable. Though the literature on AI men and health is limited, research that is available frequently highlights feelings of hopelessness and futility regarding diabetes, including themes of fear, fatalism, and denial [44]. In other populations hope has been hypothesized to be linked with the ability to implement goal-directed behaviors [45] and achieve well-being [46]. The hopefulness reported by these participants is, indeed, a positive finding, as hope can be a driver and sustainer of the energies and efforts required in improving and maintaining good health.

Future Directions

Findings from this study, although encouraging, are only the beginning. Group members spoke about learning more about food and exercise, changing behaviors in diet and physical activity, and connecting with others through community and social support.

Clearly, the ways they are working together is helpful for them, their families, and communities in leading healthier lifestyles. These men have created an experience for themselves that engenders hope, perseverance and strength, and they have empowered each other to reach beyond themselves. Questions posed in this investigation were helpful, but deeper questions could increase understandings about the connections between the depth of social support, the complexity of Medicine Wheel facets, and improved relationships with family and community. Future research can and should address the intricacies of each of these themes. Such research will allow for a richer, more meaningful understanding of how these men are managing and the ways in which they continue their pursuits in healthy living.

In addition to asking different questions, our knowledge and understanding of what aspects are most essential and helpful are limited. Our participants identified several aspects of the group that had been helpful (e.g., social support, interacting with community and family, exercise, education about diabetes, nutrition). However, at this point it is unknown if one particular aspect(s) is either more helpful or perhaps serves as a stronger catalyst for the other aspects of the group. Additionally, it could be that other aspects of the research are the most important (e.g., the collaborative processes of community-based participatory research, humor within the group, notions of balance or reclaiming identity). It is also possible that beneficent change comes from a combination of each of these factors. Future research can clarify these important questions.

Limitations

As with any study, the one we report here carries with it limitations that are important to consider. First, our sample size was small. The focus of this project was solely on the men participating in both the EMAIDI and FEDS groups. While the group is small in number, rich data were still obtained about AI men’s perspectives on health, community, and the relationships between the two. Second, our sample is not representative; while findings of this study are not generalizable, they are transferable. The themes of balance, for example, represent tenets that align with core aspects of almost every AI tribe and culture. Themes about the importance of family and community that surfaced are also essential parts of many AI cultures.

Finally, as is common in any qualitative study, it is important to consider biases in the identification and interpretation of coding methods, themes, and results. To minimize researcher bias, we used multiple coders throughout the process of analysis. Each coder worked independently, and then themes were compared, discussed, and negotiated as a team. While this does not eliminate biases, it does significantly minimize them [26,29,31,32].

Conclusion

As professionals and community member’s work together in community-based participatory research to create interventions that neither could create without the other, a purposeful integration of participants’ respective wisdom, lived-experience, and energy is allowed to emerge. As participants in the group described here have engaged with each other, the FEDS program, and other members within the larger EMAIDI initiative, they have gained knowledge, changed behaviors, reclaimed hope, and created circles of support and belonging in defiance of the disease that once took away their people’s hope and plagued their community’s health.

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References

- Williams SG, Schmidt DK, Redd SC, Storms W (2003) National Asthma Education and Prevention Program, Key clinical activities for quality asthma care. Recommendations of the National Asthma Education and Prevention Program. *MMWR Recomm Rep* 52: 1-8.
- National Diabetes Statistics (2007) National Institute of Diabetes and Digestive and Kidney Diseases, NIH.
- Health Affairs (2005) Indian Health Service Indian Health Service Innovations Have Helped Reduce Health Disparities Affecting American Indian And Alaska Native People Trends in Indian Health. Rockville.
- Jiang L, Beals J, Whitesell NR, Roubideaux Y, Manson SM (2008) AI-SUPERFPF Team (2008) Stress burden and diabetes in two American Indian reservation communities. *Diabetes Care* 31: 427-429.
- Sahmoun AE, Markland MJ, Helgeson SD (2007) Mental health status and diabetes among Whites and Native Americans: is race an effect modifier. *J Health Care Poor Underserved* 18: 599-608.
- American Indian and Alaska Native Data and Links (2010) United States Census Bureau.
- National Institute of Health (2010) Health Promotion among Racial and Ethnic Minority Males (R21). Department of Health and Human Services, NIH.
- Agency for Healthcare Research and Quality (2004) Community-Based Participatory Research: Assessing the Evidence. Rockville, MD.
- Department of Health (2005) Creating a Patient-Led NHS: Delivering the NHS Improvement Plan. London..
- Read S, Maslin-Prothero S (2011) The involvement of users and carers in health and social research: the realities of inclusion and engagement. *Qual Health Res* 21: 704-713.
- Lewin K (1947) Frontiers in group dynamics: II. Channels of group life: Social planning and action research. *Hum Relations* 1:143-153.
- Wegleitner K, Schuchter P, Prieth S (2015) OA51 Caring community in living and dying - engaging communities through participatory research, an austrian case study. *BMJ Support Palliat Care* 5 Suppl 1: A16.
- Wallerstein N, Duran B (2009) Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Public Health*. 100: S40-S46.
- Mendenhall TJ, Berge JM, Harper P (2010) The Family Education Diabetes Series (FEDS): community-based participatory research with a midwestern American Indian community. *Nurs Inq* 17: 359-372.
- Castro S, Toole MO, Brownson C, Plessel K, Schauben L (2009) A diabetes self-management program designed for urban American Indians. *Public Heal Res Pract Policy*. 6: 1-8.
- Garwick AW, Auger S (2003) Participatory action research: the Indian Family Stories Project. *Nurs Outlook* 51: 261-266.
- Goins RT, Garrouette EM, Fox SL, Dee Geiger S, Manson SM (2011) Theory and practice in participatory research: lessons from the Native Elder Care Study. *Gerontologist* 51: 285-294.
- Potvin L, Cargo M, McComber AM, Delormier T, Macaulay AC (2003) Implementing participatory intervention and research in communities: lessons from the Kahnawake Schools Diabetes Prevention Project in Canada. *Soc Sci Med* 56: 1295-1305.
- Lewin K (1946) Action Research and Minority Problems. *J Soc Issues* 2: 34-46.
- Bradbury H, Reason P (2003) Action Research. *Qual Soc Work*. 2: 155-175.
- Laveaux D, Christopher S (2009) Contextualizing CBPR: Key Principles of CBPR meet the Indigenous research context. *Pimatisiwin* 7: 1.
- Mendenhall TJ, Doherty WJ (2005) Action research methods in family therapy. In: Piercy F, Sprenkle D, (Eds) *Research Methods in Family Therapy* (2nd Edn) New York, NY: Guilford Publications pp: 100-117.
- Montoya MJ, Kent EE (2011) Dialogical action: moving from community-based to community-driven participatory research. *Qual Health Res* 21: 1000-1011.
- Scharff DP, Mathews K (2008) Working with communities to translate research into practice. *J Public Health Manag Pract* 14: 94-98.
- Strickland C (2006) Challenges in Community-Based Participatory Research Implementation. Experiences in Cancer Prevention with Pacific Northwest American Indian Tribes. *Cancer Control* 13: 230-236.
- Creswell J (2007) *Qualitative Research Design: Choosing among Five Approaches*. Thousand Oaks, CA.
- Poupart J, Baker L, Horse JR (2009) Research with American Indian communities: The value of authentic partnerships. *Child Youth Serv Rev* 31: 1180-1186.
- Trimble JE (2009) The Virtues of Cultural Resonance, Competence, and Relational Collaboration With Native American Indian Communities: A Synthesis of the Counseling and Psychotherapy Literature. *Couns Psychol* 38: 243-256.
- Kvale S, Brinkmann S (2009) *Interviews: Learning the Craft of Qualitative Research Interviewing*. (2nd Edn) Los Angeles, CA.
- Morgan DL, Spanish MT (1984) Focus groups: A new tool for qualitative research. *Qual Sociol* 7: 253-270.
- Crabtree B, Miller W (1993) *Doing Qualitative Research*. Thousand Oaks, CA.
- Creswell J (1994) *Research Design: Qualitative & Quantitative Approaches*. Thousand Oaks, CA: Sage Publications.
- Kvale S (1997) *Interviews: An Introduction to Qualitative Research Interviewing*. Thousand Oaks, CA: Sage Publications.
- Pope C, Ziebland S, Mays N (2000) Qualitative research in health care. Analysing qualitative data. *BMJ* 320: 114-116.
- Agar M (1996) *The Professional Stranger: An Informal Introduction to Ethnography*. New York: Academic Press.
- Engel GL (1979) The biopsychosocial model and the education of health professionals. *Gen Hosp Psychiatry* 1: 156-165.
- Kattelmann KK, Conti K, Ren C (2010) The Medicine Wheel nutrition intervention: a diabetes education study with the Cheyenne River Sioux Tribe. *J Am Diet Assoc* 110: S44-51.
- Robinson JD, Turner JW, Levine B, Tian Y (2011) Expanding the walls of the health care encounter: support and outcomes for patients online. *Health Commun* 26: 125-134.
- Venner KL, Feldstein SW, Tafoya N (2008) Helping Clients Feel Welcome: Principles of Adapting Treatment Cross-Culturally. *Alcohol Treat Q* 25: 11-30.
- Yip J, Martin R (2006) Sense of humor, emotional intelligence, and social competence. *J Res Pers* 40: 1202-1208.
- Keltner D, Young RC, Heerey EA, Oemig C, Monarch ND (1998) Teasing in hierarchical and intimate relations. *J Pers Soc Psychol* 75: 1231-1247.
- Nezlek JB, Derks P (2001) Use of humor as a coping mechanism, psychological adjustment, and social interaction. *Humor-Int J Humor Res* 14.
- Romero EJ, Cruthirds KW (2006) The Use of Humor in the Workplace. *Acad Manag Perspect* 20: 58-70.

44. Cavanaugh CL, Taylor CA, Keim KS, Clutter JE, Geraghty ME (2008) Cultural perceptions of health and diabetes among Native American men. *J Health Care Poor Underserved* 19: 1029-1043.
45. Snyder CR (2000) The Past and Possible Futures of Hope. *J Soc Clin Psychol* 19: 11-28.
46. Gilman R, Dooley J, Florell D (2006) Relative levels of hope and their relationship with academic and psychological indicators among adolescents. *J Soc Clin Psychol*. 25: 166-178.