

Community-Based Participatory Research (CBPR) partnership with faith-based organizations to address obesity and glucose control

Carmen Stokes, RN, Ph.D., FNP-BC, CNE

Associate Professor, School of Nursing

University of Michigan (Flint Campus)

303 Kearsley St., 2180 William S. White Bldg

Flint, MI 48502

(810) 762- 3420

stokesca@umich.edu

Kristi Jo Wilson, RN, Ph.D., FNP-BC

Assistant Professor, School of Nursing

University of Michigan (Flint Campus)

303 Kearsley St., 2180 William S. White Bldg

Flint, MI 48502

(810) 919-2313

kigeorge@umich.edu

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Corresponding author - Kristi Jo Wilson, RN, Ph.D., FNP-BC

6443 Dalton Drive

Flushing MI 48433

810-919-2313

kigeorge@umich.edu

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Abstract

Objectives: To explore the *lived* (narrative) experience of obesity and/or diabetes mellitus within focus groups consisting of individuals and community support persons residing in

Genesee County, Michigan

Design: Qualitative study, using Community-Based Participatory Research (CBPR) methodology to design and conduct focus group interviews

Sample: Nineteen participants from faith-based organizations (FBOs) in Genesee County

(74.5% Caucasian, 3.0% Hispanic American)

Measurements: Semi-structured narrative focus group interviews, using thematic coding and qualitative analysis software (Otter.com)

Results: Participants from diverse FBOs revealed barriers that prevent them from reaching their weight goals and preventing or controlling diabetes. A shared theme included the concern that providers do not actively inquire about patient concerns at appointments, and they fail to offer practical strategies beyond pharmaceutical interventions.

Conclusion: Focus group interviews with community residents revealed issues and barriers patients and their support persons face in healthcare experiences. Utilizing CBPR (methodology) is an opportunity for advanced practice nurses [healthcare professionals] to co-create strategies and interventions with the community that can assist them in successfully reaching their weight loss and diabetes prevention goals.

Key Words: CBPR, faith-based organizations, focus groups, glucose control, obesity, lived experience

Introduction

According to the Centers for Disease Control ([CDC], 2018) obesity and diabetes mellitus remain chronic health conditions for nearly 32 million Americans. Additionally, obesity (defined as body mass index > 30) increases one's risk of being diagnosed with type II diabetes (T2D) by three to seven times (Bhupthiraju & Hu, 2016). Obesity and diabetes also increase the risk for other chronic health conditions, including high blood pressure, heart disease and stroke (CDC, 2018). In one study, 46% of participants were able to achieve remission of their diabetes secondary to weight loss (Hye-Cheon Kimcheon et. al, 2008). Despite an abundance of information on how to successfully lose weight, maintain a healthy weight, and prevent or reduce the experience of diabetes mellitus; obesity and diabetes remain a public health crisis.

Background

The incidence and prevalence of obesity has been correlated with socioeconomic status (Gonzales-Zacarias et al., 2016), consequently, urban, and rural environments tend to have higher rates of obesity than some of their suburban counterparts (CDC, 2018). Factors contributing to this disparity include food deserts (Houle, et. al., 2016), inadequately built environments (Amuda & Berkowitz, 2019), higher expense of fruits and vegetables (Bhupahiraju & Hu, 2017), and diminished access to, or discretionary income for, fitness activities (de Souza de Silva, et. al, 2018).

As of 2018, the State of Michigan was in 10th place for the highest obesity rate in the United States. Genesee County (which encapsulates Flint, Michigan, home of the 2016 water crisis), reports obesity rates for adults at 32.5% and obesity rates for children as 12.5%

(MDHHS, 2017). Since the 2016 water crisis, not only have obesity and diabetes rates in Flint, Michigan remained elevated; but inequities in resources and access to healthcare, fitness, and nutrition have persisted. Chronic health conditions related to obesity and diabetes account for approximately \$400 billion dollars annually (O'Connell & Mason, 2019); therefore, preventative health care practices are essential to improving patient health status

and health outcomes, which will ultimately reduce annual health care expenditures.

Public and primary health care providers have been charged with the task of positively impacting patient achievement and maintenance of healthy weights, as well as reducing the incidence of diabetes (Healthy People, 2020). Despite the need for healthy nutrition and physical activity information to be taught in clinical settings, medical providers have limited time to devote to patient health education during appointments. Nutrition education accounts for merely 19- 21 hours of the entire 40,000 hours of medical school education (Devries, et al., 2019), which has been shown to affect physician provider confidence in addressing such issues with patients (Hanson et. al, 2015). This lack of preparation and/or confidence may consequently have an impact on patient

health goals and outcomes related to weight loss, maintenance, and/or the control or prevention of diabetes.

Literature Review

Despite an abundance of research related to obesity and diabetes, there is limited research exploring the patient's narrative with these health experiences. A literature review was conducted using advanced keyword searches: including Obesity, Diabetes Mellitus, Lived Experience, community based participatory/ engaged research, community-based organizations, faith-based organizations, and diabetes comorbidities. The CINAHL database was searched using a combination of boolean terms. Initially over 3,700 results were identified. Results were further limited utilizing the advanced search option, including "and." The results were given parameters of peer-reviewed publications in the last five years and in English language. The search was reduced to 20 items when specifically searching for obesity, diabetes, and community based participatory research. Substituting for 'community engaged research' yielded slightly different results and adding the 'lived experience' limited the search to only two items.

Narrative voices are legitimate sources of research data and focus groups allow participants to share "realities of their environment and experience," which can inform change (Israel et. al, 2012, p. 147). Given this truth, we are wholly committed to capturing the authentic voice of community residents' experiences with barriers related to weight (loss) goals, as well as diabetes prevention or control, to generate evidence-based recommendations for providers. Public health and advanced-practice nurses are in an ideal and unique position to embrace the methodology of CBPR because community involvement gives voice to the priority issues as lived by community members (Enriquez, Remy, & O'Conner, 2018). Health promotion interventions are most successful when they are faith-based (Hye-Cheon Kimcheon, et al., 2008), and nurses can design the most ideal interventions for vulnerable populations. The nurse researchers decided to approach faith-based organizations in different socioeconomic, cultural, racial/ ethnic, and physical locations within Genesee County to compare and contrast the experiences and perspectives of local residents. Utilizing their community and academic networks, the authors identified three unique populations: African American, Caucasian, and

Hispanic American congregations.

Research Questions/ Specific Aims

There are limited studies that explore the perspective of those who live with obesity and diabetes. **The specific aims of this research study include:**

1. Understanding the *lived* (narrative) experience of obesity and/or diabetes mellitus within focus groups consisting of individuals and community support persons living in Genesee County, Michigan

2. Identifying specific barriers and obstacles revealed by Genesee County residents that prevent patients from reaching their goal of weight loss and/ or glucose control
3. Translating research data into practice recommendations that specifically address the health and education strategies needed by patients from a community perspective

The authors utilized community based participatory research (CBPR) to engage local Genesee County residents within a focus group setting, in sharing their lived experience as community members, including barriers that have prevented them from reaching their weight goals and maintaining normal glucose control.

Sample

For our target population, we focused on diverse faith-based organizations (FBOs) in Genesee County. As nurse practitioners who live and work in urban communities ourselves, we desire to involve the family and community residents in educational approaches for treatment of obesity because studies have shown a positive effect when family support systems are included in patient education (Alston, et al, 2012; Trief, et. al., 2016). It has also been shown that faithbased organizations provide strong community support in the areas of health promotion and interventions (Villatoro et. al, 2016).

The inclusion criteria required participants to be 18 years of age or older, a member or neighbor of one of the selected Genesee County FBOs, and either personally experiencing or the support person for someone experiencing obesity and/ or diabetes. English was not required as the primary language because we were interested in a target population that included

Hispanic American participants.

Theoretical Framework

Working with faith-based and ethnically diverse populations requires a theoretical framework that encompasses the unique characteristics of both the target population and research design. The original CBPR Conceptual Logic Model (2008) was used to conceptualize this study design because of its comprehensiveness. For example, the authors were careful to consider socio-economic, cultural, and environmental factors unique to the community since Flint and the remainder of Genesee County is ethnically, culturally, and financially diverse. Although Flint

city proper has a higher African American population, there are also small, but distinct Hispanic American and Caucasian-American groups thriving in the city and surrounding county. The historical context of the community, including the recent 2016 Water Crisis, is also an important consideration. Researchers, advocates, and journalists have concurred that: 1) it is unlikely this type of egregious incident w/could have occurred in wealthier, whiter (less diverse) communities, and 2) Flint and surrounding county residents are experiencing significant post traumatic impact following

the water crisis. Consequently, community mistrust makes it challenging to persuade residents to seek, trust, or accept health care (Goodnough & Atkinson, 2016), or to believe that national and local governance policies are designed to protect them as residents.

Understanding the university and community's capacity and readiness to engage certainly influenced how the researchers approached this project. The perceived severity of obesity and diabetes (i.e., health issues) as evidenced by both statistical and anecdotal data, helped to drive the focus of this project. We were able to leverage individual dynamics including our core beliefs, cultural identity, and humility, as well as having a favorable reputation in the community when conducting our needs assessment, and when identifying and connecting with key community leaders. Our prior work with CBPR allowed us to understand how to identify power, how to propose resource sharing, how to ensure diversity, as well as develop academic university- community partnership agreements. Instead of traditional community-based organizations (CBOs), we elected faith-based organizations due to their historical success with improving health prevention and promotion among faith participants. In addition, due to the broken trust between the Flint community (Genesee County) and political governance; we felt it was imperative to elect partnerships with local churches who have,

despite these recent issues, continued to sustain trust in the community.

Attention was given to CBPR design, thereby promoting mutual engagement, equitable contribution, voice, and community satisfaction. Our goal for outcomes included giving voice to the lived experience, improving health disparities (i.e., reduction of obesity and experiences of diabetes), as well as capacity and system changes. We wanted the FBOs to have access to advanced knowledge and fiscal resources, as well as any mentoring needed to help congregants develop sustainable health promotion programming. Additionally, we wanted to impact system change- by educating providers about the true barriers faced by patients, so they could then tailor their patient education to community needs identified through evidence and data collection.

Methodology

The authors elected a CBPR research protocol because utilizing a CBPR approach ensures that the community stakeholders can assist in the research design, data gathering, analysis, and dissemination (Belone, et. al, 2018). This was critical because, through our interactions, focus group participants revealed feelings of exploitation over the last four years by universities, media, state government, and charitable organizations who have become involved in Flint and the water crisis for their benefit, but not that of the community (personal communication, community resident, October 16, 2019).

Approval for this study was obtained through the Office of Research Health Sciences and Behavioral Sciences Internal Review Board. A community engagement grant was later obtained for five thousand dollars and used to purchase incentive gift cards for focus group participants from

each congregation, as well as allocate seed funding for each congregation to design and sustain a health promotion activity (HPA) based on focus group data.

Design

We utilized a focus group approach, planning three separate one-hour interviews for each congregation. Prior to beginning the first session we met with the leader of the church (i.e., the priest or minister) to explain the study and seek approval. Once approval was granted, we explained the study, and a signed informed consent was obtained from all focus group participants and held the first session. During the focus group sessions, semi-structured interview questions were used to initiate the conversation, but the discussion was allowed to unfold organically by the focus group members. One nurse researcher served as the moderator, and the other was the note taker for each session. At the conclusion of the third session, participants were given a \$10 gift card to a local grocery store chain.

Analytic Strategy

Data was analyzed using several qualitative research method strategies. All focus group sessions were audio-recorded and written notes were taken during each session. Within 30 days of the focus group, one of the researchers and university assigned GRSA listened to the audio recordings to correct and/or complete the notes, transcribing them into a typed document. Later, all audio recordings were uploaded into OTTER.com software and typed transcriptions were generated for each focus group meeting. Both nurse researchers independently analyzed the session notes and transcriptions according to qualitative research protocols, resulting in thematic coding. Themes were compared, discussed, and finalized for synthesis. Some key words were combined and a research poster identifying the top themes was created to share the findings with participating congregations, as promised. The nurse researchers met stakeholders to share, discuss, and corroborate initial themes from the data analysis, as well as collaborate to determine next steps of the partnership (i.e. designing a sustainable activity) in-line with CBPR principles. Four major themes were identified across congregations through data analysis.

Results

Theme 1: Failure to Educate

According to participants, most of them have had the same physician provider for many years. When asked specifically about who they receive their care from, over 90% of participants reported having a Medical Doctor (M.D.). Many suggested that they were not familiar with a nurse practitioner and reported feeling uneasy when “forced” to see a non-physician. Typically, they didn’t like it because they believed the doctor (M.D.) was the most qualified. One participant, whom we will call “Perry” states “We do what the doctor tells us is best. They have expert education, so we trust them- you know? But, the longer you go to a doctor the more they rush you through the appointment; instead of asking you what you are doing to lose weight or even suggesting ways we can lose weight or improve our diet, they just remind us that we are ‘fat,’ obese, whatever and that we need to do something or it will cause us to die sooner.”

Further inquiry by the researchers revealed that the few patients who had experienced appointments with nurse practitioners, appreciated them because the appointment time lasted longer and felt more tailored to their needs. However, they admitted previously holding a slight preference to see a physician because they believed there was superior education and patient outcomes. When informed that research has shown nurse practitioners often score higher in patient satisfaction, patient outcomes, and health promotion and disease prevention (Kraus & DuBois, 2017), many participants requested to learn more about their scope of practice and how to find one in their area. The participants were “excited” to learn that often nurse practitioners spend approximately 20-30 minutes per patient encounter compared to the usual 10 minutes with physician providers. John agreed, “They (physicians) rush you through and don’t really ask you anything. Sometimes I have questions or want information but by the time I think of my question they have left the room and don’t come back.” Sara concurred, “Just because I’ve been seeing you a long time does NOT mean you should assume you know what I want to discuss or need- without asking me... they don’t ask, they state the obvious and walk out. Appointment over.”

Maria suggested that she learned more helpful health information from the questions she posed to us at the end of the focus group sessions than she had the last five years of seeing the physician provider. “You explained the relationship between my diet and both obesity and diabetes so clearly, if I had known that I would have gotten serious about working on this years ago.”

Theme 2: Access to Healthy Food

Perry shared that a news report helped him understand he needed to eat more ‘organic’ fruits and vegetables, but he explained, “Who can afford that? I mean, really? I try to get a few extra fruits and vegetables in, but not organic and organic is what you need....” Robert stated,

“You all shared how we can soak and remove the pesticides from our regular fruit- why doesn’t the doctor tell us that at our appointments?”

Research has shown that organic fruits and vegetables are approximately 54% higher in cost than regular items (Mirkin, 2021). In addition, the Healthy Environments Partnership (hepdetroit.org, 2021) demonstrated that people who reside in urban and lower socioeconomic neighborhoods are less likely to have access to organic fruits and vegetables. In addition, residents in such communities also have complained that when fruits and vegetables are available, they tend to be in poorer quality and rot soon after purchase when compared to suburban stores. Carmen shared an example, “I’ve lived in the city and in the suburbs. When I moved back to the city after suburban living, I would drive 20 minutes back to the suburban grocery store because juice and veggies were significantly cheaper, like- worth the short drive, but what about the people who don’t have that option because they can’t drive to another neighborhood?”

In recent years certain communities have been labeled ‘food deserts,’ to indicate that they are barren of fresh, healthy food. Instead, they are inundated with gas stations, convenience stores, fast food and expensive mom-and-pop (non-chain) grocery stores. Much of Genesee County fits the criteria for a food desert (Feeding America, 2021), where approximately 17% of

the population face insecurity in obtaining regular nutrition (N.A., 2017).

In addition, urban/ inner city areas also tend to have more fast-food restaurants and options available for residents. The foods most affordable tend to be fast food and packaged options. Over 87% of the research participants agreed that it is cheaper to buy a burger meal combo than to order a salad with water as a drink. One participant noted, “It makes me mad! I’m retired and must watch my income. I’d like to have a salad, but ordering the combo is more affordable and keeps me full for a longer period of time” Participants shared it is almost impossible to find fresh fruit as a snack option in convenience stores or gas stations. Instead, they find soda, candy, and other processed foods immediately near the entrance door and cash register, causing them to impulse buy- even when they originally had strong commitment to healthy eating and weight loss. Ruth shared, “There is one gas station that sells bananas or apples sometimes, but you have to walk far in the store toward the back, and then the bananas are usually too ripe (brown) for my preference.”

Theme 3: Inadequately built environments

Several of the county residents explained that they have lived in the community for a long time; consequently, they’ve seen a steady decline in the beauty and vibrancy of the community. “When the auto plants were here, Flint was a desired place to live. Incomes were high, community commitment was high, and there were great city services. When we lost industry, we lost everything. Sidewalks and parks are in poor repair, things are poorly lit and generally not safe. We would like to bike ride, walk, or run outside but I don’t trust it.” Several other participants agreed, stating that they have purchased treadmills and stationary bikes for home. A participant added, “...but it’s not the same. I want to work out in the fresh air, but safety comes first. Even if you call the police, it takes them too long to come, if they make it at all.” Other urban research has pointed

to how the built environment contributes to limiting resident outdoor activity, and that feeling safe is one of the main deterrents for community member's ability to engage in free and/or low-cost physical activity (Healthy Environments

Partnership, 2015).

Theme 4: Lack of Trust

Many residential communities have endured mistreatment from local, state, and federal government agencies. Examples include the case of Erin Brockovich against the Pacific Gas and Water Company (poisoning local water supply) and the Tuskegee experiment, which involved the government intentionally inoculating the Black male research participants with Syphilis disease (or failing to provide the antibiotic cure available) merely to study the course of the disease. Most recently, the 2016 Flint Water crisis (according to federal indictments, local officials were aware of the poisoned water supply, but kept that information confidential). Many of the larger corporations in Flint performed independent water testing, halted all employee consumption of local water, instead providing bottled water without making this concern public.

Epidemiologists have demonstrated that the damage from Legionnaire's disease and lead poisoning in children has caused traumatic and long-lasting effects on the community; certainly, impacting their ability to trust governmental agencies created to protect them- regardless of racial and ethnic background. Because initially the local and state government, as well as health care professionals, insisted the water was safe while dismissing resident concern, there is lingering distrust. As Mary challenged, "doctors want you to follow their directions. They don't want to talk with you, collaborate and decide together; instead, it's an authority approach. Except, we can't trust

you because you lied. I mean, except the pediatrician who was the whistleblower....” The pediatrician Mary referenced was Dr. Mona Atisha, who consistently relayed her concerns given observations of her patient presentations of significant rashes in the Flint area.

Discussion

The findings from our research indicate that despite diverse geographic, racial, socioeconomic, and spiritual backgrounds, barriers converge around shared themes. It is imperative that health care providers have a deeper understanding of the barriers and obstacles that patient (in the community) face to tailor their approach and health education strategies to these needs. Additionally, it is important to note that the themes described above cannot be resolved by only individual (patient) efforts. Instead, it is necessary to address these issues through policy change and provider advocacy in the public health arena. For example, lack of access to affordable fresh fruits and vegetables, inadequate built environments, targeted marketing for unhealthy food choices, and a lack of trust in the government, providers, and health education should all be important to public health officials. Public health nurses, administrators and nurse practitioners (providers) are in ideal positions to petition their local, state, and federal government representatives; as well as challenge and educate their personal

and professional organizational affiliations to eliminate health barriers on behalf of our nation.

As public health activists- nursing can lead the way in informing providers of research findings that result in improved patient advocacy. Improvements in patient-provider interactions can be enriched by changing institutional (hospital and medical practice) policy along with insurance regulations, for the amount of time allotted for patient care visits, the content and focus of such visits; as well as curriculum during provider education programs to include more knowledge and training regarding the intersection between nutrition, physical activity, mistrust, and weight control/ loss, obesity, diabetes.

Limitations

Limitations of the study include the total number of research participants (N=19) and the lack of African American/Black perspectives. Onset of the COVID-19 pandemic resulted in further physical, social, and psychological barriers that prevented community members from participating in focus groups; as well as limiting participation in some of their ongoing strategies to reduce weight and chronic disease disparities. The significant mistrust of African

Americans/Blacks in the Flint community (and onset of COVID-19) resulted in churches being unwilling to host focus groups. As a community resident explained, “We have been exploited and used for over four years by media, government, organizations, and researchers- everyone wants to come to Flint for the ways in which it benefits them, but no one is really concerned about what we need long term, not after they get what they desire” (personal communication, Anonymous,

October, 2019). Additional research and focus groups need to be held specifically with the African American/Black community residents to explore the commonality of qualitative themes.

Lessons Learned

CBPR is a complicated framework that requires sufficient time to assess, plan, and implement appropriate strategies in partnership with the community. The first important lesson learned: our research team could have created an alternative plan to address unexpected issues with securing sites to assure achieving our targeted sample. Second, it would have been helpful to invest more time with key informants prior to beginning our research to assure that the timing would have been acceptable across all target populations. Thirdly, the nurse researchers might have revived recruitment efforts using virtual approaches, such as offering GoogleMeet or Zoom meetings with potential pastors and focus group participants; as well as providing electronic or mailed gift cards at the conclusion. Fortunately, we were able to successfully advertise for the mini-grant applications through the church websites and email list-serves, as uniquely allowed by the pastors and priests.

Implications for Practice

Because obesity and diabetes affect approximately 40% of the US population and account for over \$400 billion dollars in health care costs, reducing the incidence and prevalence will decrease annual health care expenditures. By using CBPR with community stakeholders in each phase of the research process, we can invite essential participants, tailor the research design; identify community preferred health needs, as well as co-create interventions with community stakeholders to reach mutually identified health outcomes. Nurses (both public and advanced practice) in collaboration with primary care physicians, are in the unique position to deliver customized health education to targeted populations for weight maintenance, loss, and control or prevention of diabetes in the community.

The authors recommend that this research study is replicated in other urban and rural communities; and that African American/Black residents participate in focus group interviews.

Data reveals the themes identified at two of the three sites were consistent, despite ethnic, cultural, socioeconomic, and educational differences. Consequently, we further recommend that more nurse researchers utilize CBPR methodology and collaborate with community stakeholders to co-create interventions that will result in successful weight loss/maintenance, as well as the prevention or reduction of diabetes, which will ultimately decrease health care expenditures.

Conclusion

Building trust with community stakeholders, including key informants, is imperative to CBPR success. Although all research can encounter unanticipated challenges, the unprecedented experience of the COVID-19 pandemic presented unique circumstances, but CBPR methodology allowed continued community-researcher collaboration necessary to establish sustainable programs. Barriers including lack of access to affordable healthy food, targeted marketing, mistrust in government and health education, inadequately built environments, and failure of providers to discuss weight and patient concerns were identified through focus groups. These themes will be disseminated to public health and primary health care providers to improve their approach to assisting clients as well as the community, in meeting health goals.

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