

Together We Can Return to Balance

Eastern Woodlands Tribal Perspectives and Type 2 Diabetes Mellitus:

A Qualitative Study

A Dissertation Presented By

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Abstract

Purpose: This qualitative descriptive study was undertaken to describe Eastern Woodlands Native adult perspectives, health care beliefs and type 2 diabetes management experiences.

Specific Aims: The specific aims were to 1) explore and describe perceptions of type 2 diabetes among Eastern Woodland Native adults and how they relate to their understandings about the cause and treatment approaches to the disease, 2) describe how family, friends, and community intersect with type 2 diabetes management, 3) describe relationships with health care providers and 4) determine resources that would help diabetes-self management within their community.

Framework: The PEN-3 Model by Airhihenbuwa was the initial framework used for the study.

Methods: A qualitative descriptive design with maximum variation and snowball sampling was used and data was analyzed using qualitative content analysis.

Results: The overarching theme of Together We Can Return To Balance comprised five sub-themes: Coming to Know Life Paths with T2DM, Negotiating My Way Forward, Making Important Connections, Acknowledging the Imbalance, and Sticking Closer to Mother Earth illustrating physical, spiritual, and environmental health factors influencing DSM capacities.

Conclusion: Native perspectives should be viewed as a crucial contextual variation for type 2 diabetes care when developing DSMES and for improving DSM capacities in these populations.

Keywords: *Type 2 diabetes, Native health beliefs, diabetes self-management, qualitative*

An Eastern Woodlands Tribal Nation and Type 2 Diabetes Perspectives: A Qualitative
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**This study plan has been approved by the tribe prior to submission to UMMS IRB (Appendix F)*

An Eastern Woodlands Tribal Nation and Type 2 Diabetes Perspectives: A Qualitative Descriptive Study

Type 2 diabetes (T2DM) is epidemic affecting 30.3 million Americans (Centers for Disease Control/CDC, 2017). Native Americans have the highest prevalence of T2DM (15.1%) compared with other racial/ethnic prevalence; Blacks (12.7%), Hispanics (12.1%), Asians (8%) and Whites (7.4%) (American Diabetes Association/ADA, n.d.). In Native populations, we know that T2DM accounts for more serious complications than any other population subgroup (Jim, et al., 2014; Scarton & de Groot, 2017). A recent report by the United South and Eastern Tribes (USET) show that one unidentified Eastern Woodlands Tribal Nation has a 23.6% prevalence of diabetes (mostly type 2) compared with 7.2% of all other citizens in that region (USET, 2015). Associated morbidity and mortality rates continuously surpass that of the general population (Jim, et al., 2014; Shaw, et al., 2013). Many health disparities persist and social determinants of health are often not addressed in a culturally sensitive way (ADA, 2019; Caballero, 2018; Iwelunmor, Newsome, & Airhihenbuwa, 2014; Walker, Williams, & Egede, 2016). The ADA (2019) reports that 33-49% of Americans do not achieve T2DM treatment goals and several gaps for providing patient/family centered care exist.

There is little public information or research about the health beliefs and practices of Eastern Woodlands Tribes. Eastern Woodlands tribes, as other Native American tribes, have trouble managing their T2DM (ADA, 2019; CDC, 2017; USET, 2015). Understanding native perspectives has great potential to cast new and stimulating viewpoints concerning their experiences of living with T2DM (Powers, et al., 2017) and the influences of family support and community resources on health outcomes (Iwelunmor, et al., 2014). Notably, health beliefs and personal meanings are interrelated concepts of health that influence an individual's capacity to

live a healthy life (Beck, et al., 2017; CDC, 2017; Moss, 2016). Research linking these related factors are underexplored (ADA, 2019).

Purpose Statement

The purpose of this qualitative descriptive study underpinned by the PEN-3 model is to describe Eastern Woodlands Native adults with T2DM health care beliefs and management experiences living with the chronic condition.

Specific Aims

1. To explore perceptions of T2DM (affects, influences) among an Eastern Woodlands Tribal Nation and how they relate to their understandings of the cause and treatment approaches to the disease.
2. To describe how family, friends, and community intersect with T2DM management.
3. To describe health care provider (HCP) relationships in managing T2DM.
4. To determine resources and strategies from participants' perspectives that would help diabetes self-management (DSM) within their community.

Research Goals

This knowledge will help to advance our understanding of how to provide population-specific care for native adults with T2DM and as an entry point for creating targeted chronic disease management interventions (Iwelunmor, et al., 2014).

Theoretical Framework

This study's theoretical framework uses Airhihenbuwa's (1990) PEN-3 model. Airhihenbuwa's model identifies the importance of individual conceptions of health and how

belief systems intersect with health behaviors and health outcomes. Several studies using the PEN-3 model have elicited daily practices deeply-rooted in African-Americans with HIV/AIDs (Airhihenbuwa, et al., 2009), Latinas with cancer (Scarinci, Bandura, Hidalgo, & Cherrington, 2012), sub-Saharan Africans with T2DM (Foley & BeLue, 2017), American Indians/Alaska Natives with nicotine addiction (Hiratsuka, Trinidad, Avey, & Robinson, 2016) and Mexican Americans and Mexican Natives with T2DM (Melancon, Oomen-Early, & del Rincon, 2009). The PEN-3 model situates the study discreetly using lenses of positivity aimed at understanding family and community connectedness. These meanings have important implications for individuals and how they may navigate health challenges associated with T2DM.

The PEN-3 Model

The PEN-3 model situates the study using a lens of strength aimed at understanding family and community connectedness within the unique culture. Thus, it allows for contextual variation in health perspectives, beliefs, and values. The PEN-3 model has 3 domains and 3 sub-levels to each domain (Appendix A). The selected domains and respective sublevels are, a) persons, extended family, neighborhood, b) relationships and expectations and c) daily practices that may be positive, existential, negative. Airhihenbuwa describes how living among family members and community impacts health and influences personal meanings of health, meanings of relationships, and individual or family decisions and health practices (1990; Iwelunmor, et al., 2014). The PEN-3 model is different from other health belief models in that it espouses a conceptual turn for researchers to treat unfamiliar behaviors as possibly positive or existential factors in the context of values and practices relating to health beliefs (Airhihenbuwa, 1990). Different from other health belief models that categorize behavior as good or bad, and focus only on trying to change the bad, the PEN-3 model emphasizes and supports the good. Selected

domains of the PEN-3 framework were used to organize the literature review to support conducting this essential study.

Background and Significance

Diabetes management is multifaceted and ADA standards aim to improve overall health outcomes by developing self-managing capacities (Beck, et al., 2017). Evidence suggests that one's family and community resources influence T2DM health perspectives conditional upon social context of the illness and health beliefs shaped by living conditions and other social determinants (Iwelunmor, et al., 2014). Working with diverse communities requires cultural sensitivity (Caballero, 2018). Using the PEN-3 model selected domains as guideposts during the literature review has explicated evidence that one's understanding of the illness, relationships and expectations, and daily decisions about health choices are key factors in how T2DM is perceived and managed. Little is known about how Native Americans develop personal health meanings in coming to understand T2DM and its' implications for long-term risks for complications (ADA, 2019; Caballero, 2018; Edwards, & Patchell, 2009; Horowitz, 2012; Scarton & de Groot, 2017). The holistic approach to health and wellness is a highly regarded philosophy of Native American culture (Duran, 2002; Horowitz, 2012; Lowe & Struthers, 2001; Naranjo, et al., 2012). Given that nurses are trained to view patients and families in a holistic manner, this situates nurses as potential bridging agents who can advance knowledge using a holistic approach concerning the social and structural impact on health. Discovering what resources may have the greatest positive impact in daily T2DM management is underexplored in this unidentified Eastern Woodlands Tribal Nation.

Diabetes Self-Management (DSM) Community Identity

Studies have found commonalities that fortify the position of family and community dynamics impact on health (Horowitz, 2012; Iwelunmor, et. al., 2014). Perceptions of diabetes has been found to differ across ethnicities and Native Americans (including Eastern Woodlands Tribes) who consistently report that removal from a subsistence lifestyle and progressive exposure to the American sedentary lifestyle and poor diet account for the disease (Edwards & Patchell, 2009; Grandbois, Warne, & Eschiti, 2012; Malerba, 2016; Naranjo, et al., 2012). The role of traditional healing practices were found to reflect the importance of cultural aspects in the acceptance or rejection of western medicine (Moghaddam, Momper, & Fong, 2015; Satterfield, DeBruyn, Francis, & Allen, 2014; Satterfield, 2016a, 2016b). Importantly, community support for managing T2DM must address cultural needs, health beliefs and practices, and behavioral, psychological, physical and clinical factors (Powers, et al., 2017).

Diabetes self-management (DSM). Individuals have the greatest responsibility for disease management. T2DM management is an everyday background noise and resound with each dietary choice, type and amount of activity and the impact of other everyday life events, such as family and social conditions. These factors likely contribute to and influence DSM behaviors (ADA, 2019).

Persons. The challenges of T2DM includes a variety of personal factors affecting daily self-management (Wilkinson, Whitehead, & Ritchie, 2013) and increased rates of premature diabetes mortality linked to the silent progression of the disease (Chiu & Wray, 2010). Correlates include poor social support, lower socio-economic status, and the lack of health care access or use (Chrvala, Sherr, & Lipman, 2016).

Persons, Family, Friends, and Health Care Providers (HCPs). Rintala and others (2013) report that family member support styles play a central role in diabetes management.

Native American families often include extension of the immediate family including others (symbolic cousins, aunts, etc.) and the collective importance in preserving native traditions (Horowitz, 2012). However, which traditions impact overall health outcomes is largely unknown and medical treatment customs may influence T2DM self-management (Caballero, 2018).

Neighborhood. Land destruction or displacement and poor food access have been reported as the most influential variables linked to obesity and diabetes, especially among Native American youth (Bodirsky & Johnson, 2008; Edwards & Patchell, 2009). This legacy still influences the perspectives of Native contemporary thought (Grandbois, Warne, & Eschiti, 2012; Horowitz, 2012; Lombard, et al., 2014; Moss, 2016).

Relationships and Expectations

Relationships and expectations are intertwined with social determinants of health. The World Health Organization (WHO) defines social determinants of health as the conditions that influence where people live, work, grow and age. Social determinants of health, defined as the structural conditions (family, community, environment) that develop within particular regions impact health outcomes (Deatrick, 2017). Shaw, et al., (2013), found lack of social support among Native Americans led to maladaptive behaviors, such as poor self-management because of fear, misunderstandings, and lack of diabetes knowledge among family, friends, and their social networks.

Perceptions. How Native Americans perceive health resources and in what ways they use health resources (traditional and/or native) may uncover how they envision improving their health living with T2DM and more about what positive aspects of life may enhance self-

managing capacities. Caballero (2018) emphasizes the need to understand the personal/family ideas of illness and to explore why illness may be occurring.

Enablers. Eastern Woodlands Tribal traditions, like other Native traditions, have a rich history and importance to their people (Malerba, 2016). However, public knowledge may be misconstrued or misrepresented (Horowitz, 2012). The specifics of tribal knowledge are often hidden and protected (Duran, 2002; Scarton & de Groot, 2017). To be culturally sensitive, respect for privacy in discussing personal health matters becomes paramount (Harding, et al., 2011).

Nurturers. Many Eastern Woodlands Tribal Nations have successfully developed both economic and environmental enterprises thereby improving opportunities for employment, heritage preservation and grass-roots initiatives (such as traditional food access) to improve healthy living. Evidence suggests that families and communities structured as nurturing influences may help individuals with T2DM discover positive ways to cope and manage chronic illness (Horowitz, 2012; Rintala, et al., 2013).

DSM Empowerment

DSM empowerment includes better social support with strong family traditions and shared social values (Conte, Schure, & Goins, 2015; Dill, et al., 2016; Horowitz, 2012). Interventions that address the community collective understand high-value practices of the familiar and unfamiliar that families and communities deem as equitable and necessary for health (Airhihenbuwa, 1990). According to Iwelunmor, et al., (2014) focusing on positive and spiritual/existential ways of being and living should be supported as important facilitators for culturally sensitive health care interventions.

Positives. A well-established federally funded program, *The Special Diabetes Program for Indians* (SDPI, 1997) recently report reduction of complications associated with T2DM in some native subgroups (CDC, 2017). This is a promising trend. However, there is a need for more knowledge regarding how Native people adjust to a diabetes lifestyle (ADA, 2019). Understanding community, family, and individual needs as a collective entity may offer better alternatives for reaching targeted health outcomes (ADA, 2019).

Spiritual/Existential. Native American past-trauma increases diabetes risk fourfold (Scarton & de Groot, 2017). Factors found to influence T2DM health outcomes relate to understanding the complexity of illness, the impact of family and social traditions, and identifying the positive sustainable health behaviors congruent with Native values (Caballero, 2018). Importantly, each tribe is considered unique in its customs and these particulars may provide insights about the theoretical and philosophical basis for everyday living (Duran, 2002; Horowitz, 2012; Koithan & Farrell, 2010).

Barriers. Sovereign nations often lack social support and financial resources for health maintenance (Caballero, 2018). True prevalence of T2DM disease burden (cost, access) among the Native American population may be misleading due to the ubiquitous practice of ethnic misclassification (Jim, et al., 2014) and social determinants of health unaccounted for (ADA, 2019; Walker, et al., 2016). Thus, the overall prevalence of T2DM and morbidity and mortality in Native populations is not fully represented.

Methods

The aims of this study will focus on adults with T2DM from an unidentified Eastern Woodlands Tribal Nation perspective of health, health beliefs and T2DM management. The

qualitative descriptive (QD) approach is suited to understand perspectives of people (Bradshaw, Atkinson, & Doody, 2016) experiencing T2DM in the everyday.

Eastern Woodlands Tribal Nations

For an American Indian, “health is more than just physical health...it reflects the state of harmony with the external and internal world”, (Malerba, 2016, p. 99-100). The Eastern Woodlands Tribe under study is a federally recognized sovereign nation owning the knowledge of living, surviving, and preserving native language and culture in the face of historical intrusion (CDC, 2014; Malerba, 2016). This tribal nation actively engages in efforts aimed at saving the native language, protecting their sovereignty status, and developing healthy communities and sustainability of local resources on their homeland.

Tribal Benefit

The benefit to the tribal community encompasses the qualitative research approach (subjective experience) of talking about what it’s like having and living with T2DM. The opportunity to hear from individual experiences of their everyday in the management of T2DM provides a unique lens for understanding successes, challenges, and barriers. Resulting qualitative data will then be analyzed with tribal input as a step toward developing future interventions that more closely match native perspectives of T2DM management.

Qualitative Description

Qualitative description (QD) is a specific descriptive method for understanding the complex realities embedded in human experience (Sullivan-Bolyai, Bova, & Harper, 2005). In this study, the experience of living with T2DM and the positionality of being Native American suggests such a complex domain of experience. Appropriately, the goal of using QD as a

method to study Eastern Woodlands Tribal perspectives aligns with the means to provide a rich description of events that can be understood in plain language without excessive interpretation—thereby making the findings resistant to misinterpretation (crucial to representing interview data accurately) and relatable to those living with T2DM (Sullivan-Bolyai, Bova, & Harper, 2005).

This study will be conducted in the natural setting (on the tribal reservation) and follows what is termed a naturalistic approach (Bradshaw, Atkinson, & Doody, 2016; Lincoln & Guba, 1986). The researcher aims to, a) gain personal accounts of experience, b) gather subjective data as it is experienced by people by staying close to what is offered and c) participate in the overall process for understanding unique perspectives and the meaning of life events and daily living practices as told by the participants (Bradshaw, Atkinson, & Doody, 2016).

The advantage of QD is the openness to all realities as experienced by participants as verbatim accounts; an important aspect in respecting how information is shared by the Eastern Woodlands Tribal Nation. This openness to all realities often results in rich information through identification and discovery of thematic findings (Braun & Clark, 2006; Sandelowski, 2000; Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016). In this study proposal, QD semi-structured (open-ended questions) in face to face individual interviews with adult members of the tribe with T2DM are planned. Later in this proposal, the inclusion of telephone/virtual interviews with tribal members living outside the reservation region were included. This help to reach targeted sample number of completed interviews.

Sample

In this study, maximum variation sampling (type of purposive sampling) was chosen to cast a broader net for diverse viewpoints (Saldana & Omasta, 2018). In maximum variation

sampling, even a small sample of 10 can produce a large amount of rich and varied content (Saldana & Omasta, 2018). It is expected that a sample of at least 15 to be sufficient to answer the study questions and to reach information redundancy.

Inclusion criteria. Inclusion criteria are all genders who are citizens (members) of the Eastern Woodlands Tribal Nation willing to participate, aged 18 years or older, with the ability to read and understand English and who have a diagnosis of T2DM. Whether healthcare is received from the Eastern Woodlands Tribal Nation health care providers or others is not an exclusion.

Exclusion criteria. Exclusion criteria are those persons who are not members of the Eastern Woodlands Tribal Nation, and/or under 18 years old, do not have a diagnosis of T2DM, or are unable to read and understand English, including persons with cognitive impairment defined as the inability to understand and answer interview questions.

Setting

A request to use a private office setting on the Eastern Woodlands Tribal reservation to conduct private interviews has been approved (Appendix F). This region has been an Eastern Woodlands Tribal homeland for centuries. After meeting with the Tribal Nation Data Sovereignty Review Board, it is agreed that coordination of study interviews in a quiet private conference room in the reservation government center will be arranged between the researcher, participant and the assigned tribal contact designee (Appendix F).

Procedures

Working with the proposed sovereign nation requires special considerations beyond what may be planned in general population studies. Any reference to the study group in final publications will be named as “an unidentified Eastern Woodlands Tribal Nation.” After consultation with the tribe, areas of the proposal were revised to address cultural sensitivity and humility (Appendix F).

The following sections discuss recruitment and compensation, retention, data collection, data management, and finally data analysis.

Recruitment and Compensation

Recruiting members of tribes is challenging. Recruitment can depend on whether or not participants believe participating in research by identifying themselves as an affiliated tribal member is a benefit or risk (Malerba, et al., 2018).

Recruitment Announcement. In the announcement (Appendix E), the call for participants will focus on the opportunity presented to better understand the challenges of living with T2DM. The recruitment announcement will appear in official tribal publications (Eastern Woodlands Tribe C.L.M., email communication, 2018). Ongoing recruitment announcements and recruitment announcement cards (placed in the tribal health clinic) will advertise the study until the researcher has received sufficient number of study participants who have completed interviews.

Recruitment Referrals. Tribal Nation Data Sovereignty Review Board has approved an adjunct recruitment technique called snowballing (participant referral). This will occur at the end of the participant interview. The researcher will ask if there may be someone else likely to

volunteer to be interviewed. If the answer is yes, a recruitment card (Appendix E) will be given to the interviewee to pass on to the potential participant as an invitation to join the study.

Compensation. A \$50.00 Visa gift card (approved by The Tribal Data Sovereignty Review Board) will be offered to all participants who complete the interview.

Retention

Retention begins with ensuring that study participants have read and understand the research consent document and that all questions are answered. The researcher will provide a copy of the signed consent form to each participant. During interviews care will be taken to provide breaks. Sensitive subjects, such as native heritage specific to the participant, will be avoided. Interview time frames will be respected. If a sensitive subject appears that makes the participant feel uncomfortable, questions will be re-directed. Participants will also be told that confidentiality and anonymity is part of the agreement between the tribe and the researcher and that no likeness, name or other personal characteristic will be recorded. The agreed name of “An Eastern Woodlands Tribal Nation” is the only identifier to be used with information associated with this study. Periodic status reports to the tribe (or designated representative) will ensure tribal customs are respected and areas of concern can be discussed.

Data Collection

Data collection includes demographic information about age, gender, family status, occupation, education level, date of T2DM diagnosis, the presence/absence of T2DM complications, and other medical conditions. Face to face interviews will include open-ended questions developed from selected domains within the PEN-3 framework to explore health

beliefs about T2DM. Data will be gathered with an objective perspective during the interview in order to gather rich descriptions of the participants' experiences. Field notes will be taken immediately after each interview and will be incorporated into the transcripts. Reframing questions and the use of probing questions will help guide the natural progression of the interview (Appendix B). Prompting style of questioning (trying to persuade an answer in a directed way) will be avoided. Audio recording of conversations will be done to ensure accuracy of answers to interview questions.

Reflexivity. Researcher positionality using reflexivity addresses pre-conceived bias through a self-reflective process. Reflexivity is evident when the researcher uses self-awareness of self and others and *attentively* listens making field notes for questions that may or may not be asked later (Mitchell, et al., 2018). The positionality of the researcher (in a power position as the one asking questions) will be minimized by carefully constructing questions. This active type of conscious reflection will help prevent persuasive or biased questions that can become prompting rather than probing. The principal investigator of this study is entering the field as a novice to T2DM management within the Native American community. Reflexive journaling will also help maintain reflexivity regarding personal thoughts, concerns, and any methodological issues that may arise. Care will be taken to describe additional observations (such as native symbolism on clothing, or artifacts in the office space or with the participant) to protect personal identity and sacred tribal information. If protected knowledge is inadvertently described, it will be omitted if requested by the tribal data sovereignty review board prior to dissemination of study findings.

The Structure of Interview Questions. The development of interview questions are derived from each aims' focus and the selected domains of the PEN-3 model (Appendix B).

Other guiding concepts are based on Native American research literature, the clinical issue (T2DM), the setting (natural/private interviews), and the qualitative descriptive approach.

Sensitive questions will be avoided, such as inquiring about a participant's tribal heritage specifically. The tribal review board did not request any changes to the questions presented. The questions are:

- Before your diagnosis of T2DM, what did you know about the disease?
- How did you come to know you had T2DM?
- What have you been told to do to manage T2DM?
- What have you found to be helpful to manage T2DM, what gets in the way?
- Tell me a bit about who else in your family and/or friends helps with the management of T2DM?
- Tell me about your relationship with your health care provider (HCP) and how does s/he support you in the T2DM management?
- What other resources and/or supports would help you manage T2DM?

Data Management

Accuracy of interview data will be ensured by audio-recording and verbatim transcription. Microsoft and Excel programs (using a 10-step method) will be used for managing qualitative data (Ose, 2016; Appendix C). Each participant will be told that audio-recording is necessary to ensure the accuracy of verbatim accounts. Verbatim transcripts will be completed by a professional transcriptionist and compared with audio-taped results by the investigator. Protection of privacy and confidentiality is part of human subjects protection rights, but additional care will be observed and enacted in this study to avoid misrepresentation as has

occurred with a detrimental effect in the past (Harding, et al., 2011). As such, all participant information and data collected will be de-identified (or discarded if re-identification risks are deemed to exist) according to The Tribal Data Sovereignty Review Board recommendations (Appendix F). Each study participant will receive a case number and no names and/or personal characteristics will be saved. Transport of audio recordings will be done judiciously remaining with the researcher at all times and transcribed as soon as possible after the interview (Appendix C). Electronic data storage will be kept in a University of Massachusetts Medical School secure research drive (r-drive) and any paper documents will be kept in a confidential folder in a locked file in the graduate supervising faculty office at the University of Massachusetts Medical School or other agreeable and secured place.

Data Analysis

Data analysis occurs early in qualitative research and the interview transcripts are examined early on to provide ongoing data preparation prior to final analysis (Willis, et al., 2016). Field notes and other observational data will be written down during or immediately after interviews to improve the transparency and development of subsequent interview questions (Appendix B). This process captures the patterns and unique circumstances adding to the richness of everyday experiences of participants. It is expected that some revision of interview questions or the likelihood of adding new questions will be created along the way. For example, rich information appearing from one interview may inspire additional questions for subsequent interviews (Appendix C).

The benefit of this descriptive method supports a collaborative approach in connecting with tribal participants to check (during the interview) and re-check (with a random selection of

participants after themes are created) for accuracies in the interpretive re-presentation of findings. Interpretations in QD are not deep, but rather discoveries are found from the meanings in the everyday (Sullivan-Bolyai, Bova, & Harper, 2005, Willis, et al., 2016) and the process serves as an audit trail. The data analysis will use thematic coding defined as discovering meaning units along the way and categorizing these units into threads of meaning (Appendix C). Additional consensus about themes will occur with supervising faculty and consultation with the Eastern Woodlands Tribe *before* final dissemination of study results. Each step in this process adds to qualitative rigor and trustworthiness.

Establishing Trustworthiness. In qualitative research, the ownness is on the researcher to ensure design, methods, and procedures are established well enough to address credibility, transferability, dependability, and confirmability; the tenets of trustworthiness (Marshall & Rossman, 2016; Saldana, 2013; Shenton, 2004).

Credibility. In this study, the PEN-3 model has been used many times to construct research about health belief practices and perspectives on health with diverse communities (Airhihenbuwa, 1990; Cowdery, Parker, & Thompson, 2010; Iwelunmor, et al., 2014). This aspect provides a good foundation for the strength-based avenues of this qualitative inquiry (Appendix C). Contact with the study population over several months helped to establish a working relationship between tribal leadership and the researcher. Having an assigned tribal contact person (who is also nurse clinician) provides a path to assess information received by participants. Supervising faculty with expertise in diabetes health and qualitative research assures debriefing sessions during the research and provides opportunities to evaluate emerging

ideas. Checking with participants during and after the creation of themes provides additional credibility of found meanings.

Transferability. This study will be conducted with one sample of Native Americans in the Eastern region of the United States. The descriptions of Native adults with T2DM and their health perspectives will be shared in the context of a single-site qualitative study. Elements of the study may relate to future study design and interventions aimed specifically to the study group. Additional qualitative studies with this Native population would be necessary to adequately address transferability.

Dependability. Addressing the details of conducting the study will be an ongoing process that will reveal challenges, successes and barriers for conducting and implementing the study in its present form. New strategies for subsequent studies will likely emerge as the study unfolds. This information will be an important addition in the final reporting of study results.

Confirmability. The researcher will discuss and provide enough detail about the formation of themes and ideas (such as code development) generated from the text descriptions (Appendix C). Whenever possible, this process will clarify the researcher's choice of using particular descriptions of phenomena of interest and the reasons for these choices.

Ethics

Unplanned breach of confidentiality is a very small risk for all research and no absolute guarantees can be made. However, in this study, all participants will be given a case number and no names or likeness (such as personal characteristics) will be used in data collection or data analysis and publication. Final study products will be shared with the tribe to ensure quality and

confidentiality checks prior to any release of study information to the public (such as journal submission). It is important to note that the National Institute for Health (NIH) single-IRB policy does not apply to tribal nations (Malerba, et al., 2018). Data sovereignty indicates the importance of mutual understanding and agreement about ownership of study products (C. L. M., personal communication, October 17, 2018). For example, interview questions guided by the PEN-3 model may need rephrasing to enhance cultural sensitivity and reflects a safeguard measure against invasion of privacy and/or misrepresentation of the tribe. Other ethical considerations include the overt collaboration with The Tribal Data Sovereignty Review Board (Malerba, et al., 2018). Consent documents (Appendix D) have been designed according to current understanding of plain language consent and agreements made between the researcher and the Eastern Woodlands Tribal Nation. All participants will receive a copy of the consent document (Appendix D).

Institutional Review Board

This study has been reviewed and approved by the Eastern Woodlands Tribal Nation Data Sovereignty Review Board to ensure that the researcher treats the participants in an ethical manner (Appendix F). This study proposal will be submitted for review to the University of Massachusetts Medical School institutional review board presently.

Ownership of Study Products

During each phase of this research proposal development, expert consultation has been sought to ensure that research aims and procedures align to what is deemed acceptable to the tribal community. At the end of the study, data ownership would be given to the Eastern

Woodlands Tribe. All data, recordings, and transcripts will be returned to the tribe and owned by the tribe. Dissemination of study results in a published scholarly article (because this study is a doctoral dissertation) has been agreed to by the tribe with modifications (Appendix F). There are highly respected journals that may be suitable for manuscript submission, such the *American Journal of Public Health*, or the *Journal of Family Nursing*. Prior to publication, the Eastern Woodlands Tribal Data Sovereignty Review Board will review the proposed article and will provide feedback for changes to be included should there be anything of relevance to the tribe.

Conclusion

Presented here is a qualitative descriptive study proposal for understanding the perspectives of adults with T2DM from an unidentified Eastern Woodlands Tribal Nation. This tribal nation has a 23.6% diabetes incidence compared to 7.2% of other citizens of the region (USET, 2015). Many research questions aimed at understanding this disparity remain to be answered. Using the PEN-3 model serves as a viable framework for exploring the impact of living with T2DM, the importance of family support, navigating available community resources, and making sense of living with a chronic condition. Some study procedures—unique to the tribe—require tribal agreement, oversight and assurance that this proposed research relates to tribal health priorities and has the potential to ultimately benefit its citizens. Factors that influence the personal meaning of illness and how daily decisions are made are likely to indicate the levels of understanding of T2DM and the quality of self-management. Qualitative descriptive research provides a sensitive approach for exploring Eastern Woodlands Tribal perspectives and T2DM that values the *experience of the everyday* in making meaningful decisions toward achieving T2DM management goals and living a healthier life. These study results have the potential to inform interested stakeholders about the personal experiences of

living with this chronic condition. This new knowledge can be a valuable resource for future T2DM intervention development.

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Executive Summary

This was a qualitative descriptive study undertaken to explore the perspectives of Native adults with T2DM who were members of an unidentified Eastern Woodlands Tribal Nation. Semi-structured interviews (N=12) were conducted and subsequent thematic development resulted in one overarching theme and five interwoven sub-themes. The overall representation depicts the journey from finding out about T2DM diagnosis to making necessary changes to lifestyle behaviors to prevent progression of the disease. Native perspectives call for improving T2DM resources, addressing Native people's multi-generational concerns, and developing population-specific interventions that may mitigate the increasing incidence of new T2DM cases. Opportunities for nurses to develop community specific diabetes care were presented.

Summary of Changes from Proposal

1. The study plan was amended and approved on 9/29/2019 to allow for telephone interviews improving the opportunity for recruitment for tribal members living away from the reservation or who might be unable to travel for a face-to-face interview.
2. The final title was changed slightly *from* "An Eastern Woodlands Tribal Nation and Type 2 Diabetes: A Qualitative Study *to* "Eastern Woodlands Native Perspectives and Type 2 Diabetes: A Qualitative Study", thus reflecting the perspectives of individual accounts rather than an implied accounts from the Nation.
3. At the start of the study, my tribal contact person was a nurse clinician. Prior to scheduling interviews, the community outreach coordinator became the newly assigned contact person.

Dissertation Defense Slides

“Together We Can Return To Balance” Eastern Woodlands Native Perspectives and Type 2 Diabetes: A Qualitative Study

A Dissertation Presented By
Penni Patricia Sadlon

Submitted to the Graduate School of Nursing University of Massachusetts Medical
School in partial fulfillment of the requirements for the degree of
Doctor of Philosophy Nursing

Acknowledgments

Dissertation Committee

- Dr. Susan Sullivan-Bolyai, DNSc, , RN, FAAN
- Dr. James Fain, PhD, RN, BC-ADM, FAAN
- Dr. Denise Charron-Prochownik, PhD, RN, CPNP, FAAN

The Eastern Woodlands Tribal Nation

Introduction

- Type 2 diabetes mellitus (T2DM) incidence continues to rise in Native populations
- Eastern Woodlands Tribal Nation has a 24% T2DM prevalence (USET, 2016) with higher morbidity and mortality (Jim, et al., 2014; Scarton & de Groot, 2017)
- ADA standards call for interventions that increase diabetes self-managing (DSM) capacities (Beck, et al., 2017)
- Native people are less likely to adopt conventional diabetes self-management education (DSME; Jones, et al., 2020)

Purpose

The purpose of this qualitative descriptive study was to explore perspectives of Eastern Woodlands Native people with T2DM in the context of health beliefs, T2DM disease self-management, and family and extended community connections present.

Research Aims

AIM – 1

Explore perceptions of T2DM (affects, influences) among an Eastern Woodlands Native people and how they relate to their understandings about the cause and treatment approaches to the disease

AIM – 2

Describe how family, friends, and the community intersect with T2DM management

AIM – 3

Describe health care provider (HCP) relationships in managing T2DM

AIM – 4

Determine resources and strategies from participants' perspectives that would help diabetes self-management (DSM) within their community

Background and Significance

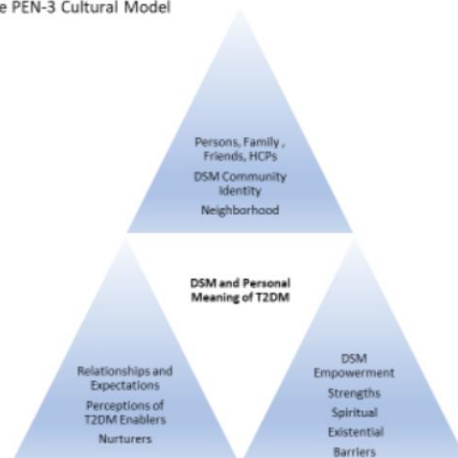
- Evidence suggests that family and community resources influence T2DM health perspectives which is conditional upon social context of the illness and health beliefs shaped by living conditions (Iwelunmor, et al., 2014).
- Native traditions impacting overall health outcomes is largely unknown and may influence T2DM self-management (Caballero, 2018).
- Native people receive inadequate DSMES, thus develop low capacity DSM and unmet treatment goals (Jones, et al., 2020).
- In depth studies within Native community settings is needed to expand knowledge about factors affecting DSM capacity building (Caballero, 2018; Schure, et al. 2019; Jones, et al., 2020).

Where is the GAP?

- Many Federal diabetes resources are not available or accessible to all Native groups (ADA, 2019)
- Conventional diabetes programs are often aimed at individuals and fail to target families and communities with multi-generational concerns (ADA, 2019)
- Some programs don't include community stakeholders to the degree needed for adequate education and ongoing support (ADA, 2019)

Framework An Eastern Woodlands Tribe

- Selected domains of the PEN-3 Cultural Model



- **Airhihenbuwa's (1990) PEN-3 Cultural Model** identifies the importance of individual conceptions of health and how belief systems intersect with health behaviors and health outcomes. The PEN-3 Cultural Model is aimed at understanding family and community connectedness within the unique culture. Thus, it allows for contextual variation in health perspectives, beliefs, and values.

Research Design

- This study used a qualitative descriptive (QD) design (Sandelowski, 2000)
- The advantage of QD is the openness to meaningful realities as experienced by participants which is an important aspect for showing respect to each Native person and the shared information
- The QD method was appropriate for this study of contextual factors because the aims were to discover held beliefs and shared perspectives of having and living with T2DM
- The PEN-3 Cultural Model guided interview question development and beginning categories in alignment with study aims

Inclusion/Exclusion Criteria

Inclusion	Exclusion
Eastern Woodlands Tribal Member	Non-Native
> 18 years old	<18 years old
Diagnosis of T2DM	No diagnosis of T2DM
English Speaking	Non-English Speaking
Able to read and understand English	Unable to read and understand English
Cognitively Intact	Cognitively Impaired

Methods

Approvals

Tribal approval and agreements 5/6/2019

UMass IRB approval
#H00018063

Tribal member designee
assigned to assist researcher
with tribal communications

Advertising - Member-only
tribal study announcements

Recruitment

Maximum-variation sampling – a
variant of purposive sampling (Yin,
2016) and snowball sampling

Pharmacy referrals

Verbal and written consent

Face to face or telephonic interviews
(N=12)

No prior relationship with
participants

Methods

Sample Questions

What was it like for you when you were first diagnosed with T2DM?

What did you know about T2DM prior to your diagnosis?

What do you think caused the T2DM illness?

Settings

On the Reservation (n = 5)

By telephone (n = 7 US only)

Compensation

Visa Gift Card \$50 was given to all participants who completed the interview (100%)

Methods

Interviews

QD semi-structured individual interviews

The study aims and the PEN-3 model helped to guide initial question development

Telephone interviews with tribal members living outside the reservation region were included later to increase study participation

Trustworthiness (Lincoln & Guba, 1985)

Credibility – prolonged engagement – building trust – peer debriefing - member checks

Transferability – rich description

Dependability – peer review

Confirmability – audit trail

Researcher reflexivity

Researcher as instrument

The positionality of the researcher (Mitchell, et al., 2018).

Researcher bias

Reflexive Journal

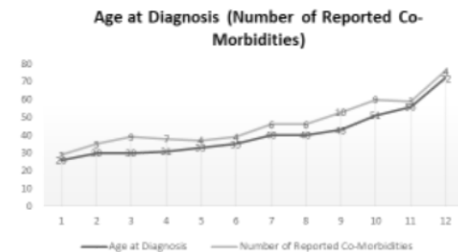
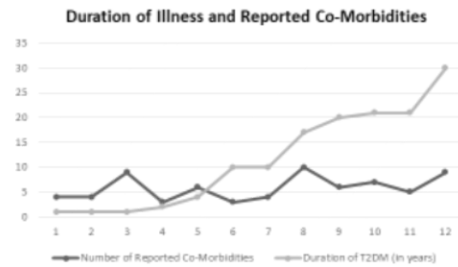
Data Analysis

- Descriptive statistics – assessing sample
- Reported co-morbidities and duration of illness
- Audio-taped professionally transcribed verbatim semi-structured interviews
- Qualitative content/thematic analysis (Yin, 2016) as an iterative process
- Information redundancy and saturation

Demographics

• Participant Characteristics N = 12

Sample: An Eastern Woodlands Tribal Nation	Membership Pool N = 2300
	Membership with T2DM N=552 (24%)
T2DM Participants N=12	0.52%
Male n=4	33%
Female n=8	67%
Age (Mn/Mdn)	
Male	36 – 72 (54/54)
Female	35 – 71 (52/51)
Marital Status	
Married/Remarried	83%
Single/Divorced	17%
Duration of T2DM illness	
<10 years	42%
> 10 - < 20 years	33.00%
> 20 years	25%
Education	
High School	27%
Some College	37%
College Degree	27%
Graduate Degree	9%

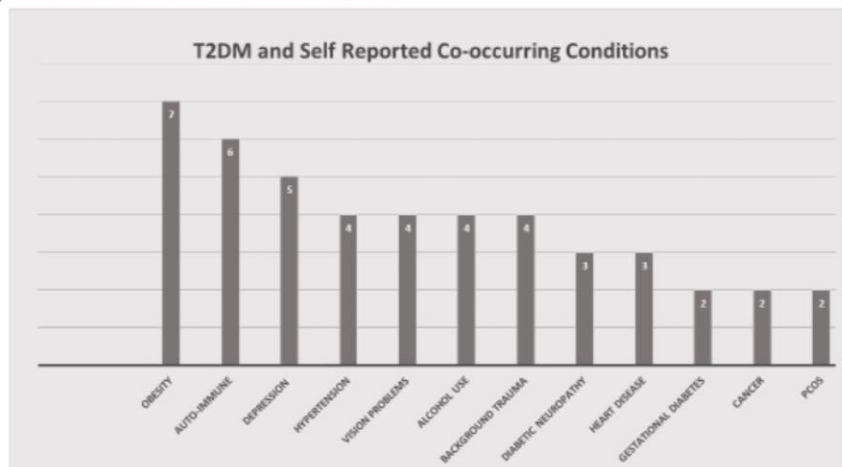


Eastern Woodlands Perspectives and T2DM

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Demographics

• Participant Characteristics – Co-Morbidities



Eastern Woodlands Perspectives and T2DM

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Results

Overarching Theme and Sub-Themes

- ***Together We Can Return to Balance***

Coming to Know Life Paths with T2DM

Acknowledging the Imbalance

Negotiating My Way Forward

Making Important Connections

Sticking Closer to Mother Earth

Overarching Theme

Together We Can Return To Balance

"Non-Natives don't walk around talking about going into the sweat lodge all the time, you know, stuff like that. So, I am gifted with the fact that my heritage way is more prone to these spiritual activities than, as far as I know many other heritages...when my body is out of balance...and it's typically out of balance all the time...I have to do other things to bring it in balance. The way I talk about it spiritually [is] what you call the four directions. And each direction has a part associated with it. Either a season... and each has a season, a color, an animal, traits..."

Coming to Know Life Paths with T2D

Diabetes Knowledge, Complexity, and Hardship

Finding Out You have Diabetes

Incomplete Diabetes Knowledge and Education

T2DM Complexity

"They took us to the classes and told us like diet changes and all that, you know. That was a little shocking. Everything that I thought would be okay to eat all of a sudden wasn't. You know what I mean? Like I didn't know that potatoes and pasta are starch and once they get into the body they turn into sugar. Or that breads did the same thing. And when they explained that, I just couldn't believe that something like that would be dangerous for the body when you're diabetic."

Eastern Woodlands Perspectives and T2DM

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Acknowledging the Imbalance

Developing Self-Responsibility

Significance of Living with T2DM

Implications for Untreated T2DM

Breaking the Silence and Talking About T2DM

Conquering Fears

"Like I say, my brother, I really wish he would, and I've mentioned it to him a couple of times, but I'm not a doctor, okay? And I figure if I tell him what I'm going through, he was very close with my dad too. And he says, "Yeah, dad had it." And I said, "You need a two by four, or a brick, or a what? Somebody have to hit you in the head? Go get tested. You may find you have it."

Eastern Woodlands Perspectives and T2DM

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Negotiating My Way Forward

Developing Self-Awareness and Action

Privacy

Coping with T2DM Alone or Without Help

Patterns of Self-Management

"When I did find out and I was pre-diabetic, I probably didn't do myself justice because I went to a nutritionist, and she was saying that I have to eat a certain way and do certain things, and I'm like yeah, I'm not doing that. Well, unfortunately in hindsight I'm now doing that because I know the ramifications, and it's not getting easier, it gets harder, and harder and harder..."

Eastern Woodlands Perspectives and T2DM

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Making Important Connections

Developing Trusting Relationships

Health Care Provider Relationships

Supportive Roles Family/My Tribe Caring Relationships

Community Relationships

"Well she is Native American and we laugh a lot about stuff but she's like, you know, why are you drinking that soda? What's wrong with you, you know? Like, (laughs) she's able to confront me but help me to laugh at the same time. So, she's helping me to get back on track. She'll bring in healthy snacks and I'll bring in healthy snacks at work. Yeah because it feels to me like Native people understand about how important food is in our culture."

Eastern Woodlands Perspectives and T2DM

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Sticking Closer to Mother Earth

Living A Quality Life with T2DM

Native Ways Past and Present Like Our Ancestors Lived

Developing a Natural State

T2DM Prevention for Future Generations

"I think our lifestyle [has] destroyed the Native American's ability for their bodies to really grasp what is going on...the food...the lifestyle, you know, I don't think we're made to do that...especially if you had Native American blood in you, you need to be outside, you need to be doing what you used to do, or simulate what it used to be."

Eastern Woodlands Perspectives and T2DM

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Sub-Themes and Dimensions

<i>Coming to Know Life Paths with T2DM</i>	<i>Acknowledging the Imbalance</i>	<i>Negotiating My Way Forward</i>	<i>Making Important Connections</i>	<i>Sticking Closer to Mother Earth</i>
Diabetes Diagnosis, Knowledge, Complexity, and Hardship	Developing Self Responsibility	Developing Self-Awareness and Action	Developing Trusting Relationships	Living A Quality Life with T2DM
Finding Out You Have Diabetes	Acknowledging the Significance and Implications of Untreated T2DM	Privacy	Health Care Provider Relationships	Native Ways Past and Present Like Our Ancestors Lived
Incomplete Diabetes Knowledge and Education	Breaking the Silence and Talking About T2DM	Alone or Without Help	Supportive Roles Family/My Tribe Caring Relationships	Developing a Natural State
T2DM Complexity	Conquering Fears	Patterns of Self-Management	Community Relationships	T2DM Prevention for Future Generations
Aim 1	Aim 1, 2, 3, 4	Aim 2 and 3	Aim 2 and 3	Aim 1, 2, 4

Eastern Woodlands Perspectives and T2DM

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Community-Specific Resources and Strategies

What community-specific resources do you think would be helpful to you and others just diagnosed with T2DM?

Aim 4 - Participant Perspectives on Community Relevant Resources

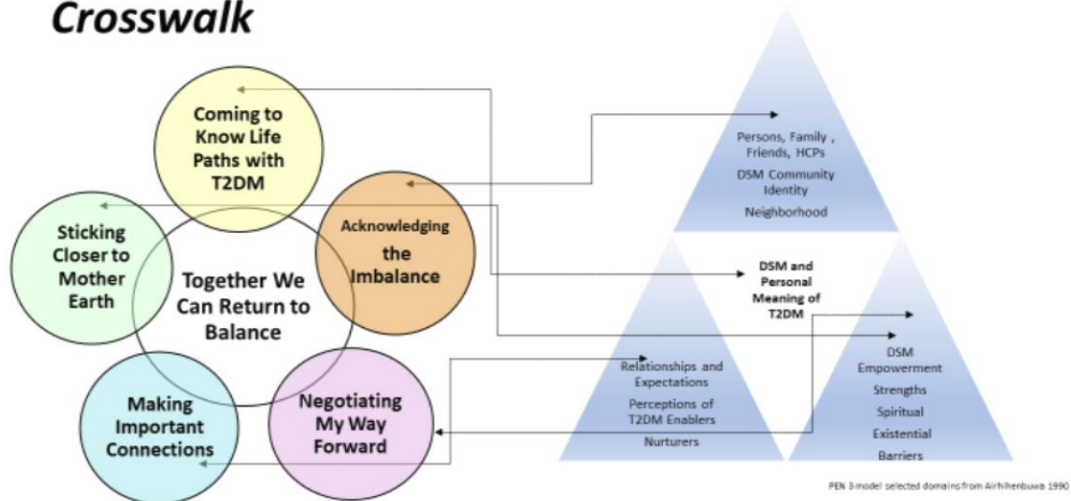
Access and Availability:

- ✓ Native Physicians
- ✓ Nurse Diabetes Education Specialist
- ✓ Native Talking Groups
- ✓ Native Cooking Classes for T2DM
- ✓ On-line Support Groups especially for Native Americans with T2DM
- ✓ Asynchronous Chat Rooms (for anonymity)
- ✓ Diabetic-friendly Food at Events
- ✓ Native Diabetes Mentors (for DSM)
- ✓ Pre-diabetes Screenings for Youth
- ✓ T2DM Events Held on the Weekends

Eastern Woodlands Perspectives and T2DM

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Thematic Crosswalk



Eastern Woodlands Perspectives and T2DM

Limitations

Perspectives represent one tribe, one region
 Privacy was an influencing factor in recruiting participants
 Family Referral Bias
 Recall Bias

Discussion

Existing Literature

Studies demonstrate poor outcomes when individuals and families lack T2DM knowledge and have preconceptions about *why the illness may be occurring* (Caballero, 2018).

Native people risk higher morbidity and mortality associated with inadequate DSME, subsequent low capacity DSM leading to unmet treatment goals, higher rates of diabetes complications, and decreased life expectancy (ADA, 2019; Jones, et al., 2020).

Focusing on positive and spiritual/existential ways of being and living should be supported as important facilitators for culturally sensitive health care interventions (Iwelunmor, et al., 2014).

To be culturally sensitive, respect for privacy in discussing personal health matters becomes paramount (Harding, et al., 2011).

In this study

Native people described incomplete T2DM knowledge

Privacy was a factor in discussing diabetes within families

Inadequate supportive resources impacted self-management capacities

Many Native people suffer from T2DM complexity and co-occurring illnesses

Health behaviors are influenced by family, community, and belief systems

Native people desire population-specific care by health care providers who are trained in Native conceptions of health and wellness

Native people have multi-generational concerns and worry about future trends of obesity and T2DM in their families

Nursing Research, Nursing Education, and Health Policy Recommendations

Nursing Research

- ✓ Intervention studies designed to improve T2DM education and support for Native people need development with special emphasis on community participation
- ✓ Focus on Native family and community involvement in conjunction with ADA (2020) diabetes self-management education and support (DSMES) strategies should guide research designs

Nursing Education

- ✓ Undergraduate and graduate nursing programs should implement culture-specific nursing paradigm concepts (person, health, environment, care) when developing nursing content for the care of Native populations with T2DM

Health Policy

- ✓ Health care delivery sub-systems for treating Native people with T2DM need to be analyzed to evaluate efficacy, efficiency and accessibility within the specific contexts of each Native community
- ✓ To alleviate upsurge in T2DM prevalence and to promote earlier DSMES, earlier diabetes screening is needed to identify pre-diabetic states in Native people

Conclusion

Study results advocate the concept *being in balance* when EA Native people convey diabetes self-management (DSM). To mitigate the impact of diabetes complications, trusting relationships and health partnerships should be developed and sustained across the duration of illness. EA Native knowledge about the cause and treatment approaches to T2DM may be further supported by integrating natural (indigenous) knowledge about health and wellness with conventional principles of diabetes care. This proposed integration presents several opportunities for nurses to advance diabetes self-management education and support (DSMES) by including Native health concepts as desirable for holistic-family-community involvement that is central toward preventing disease progression.

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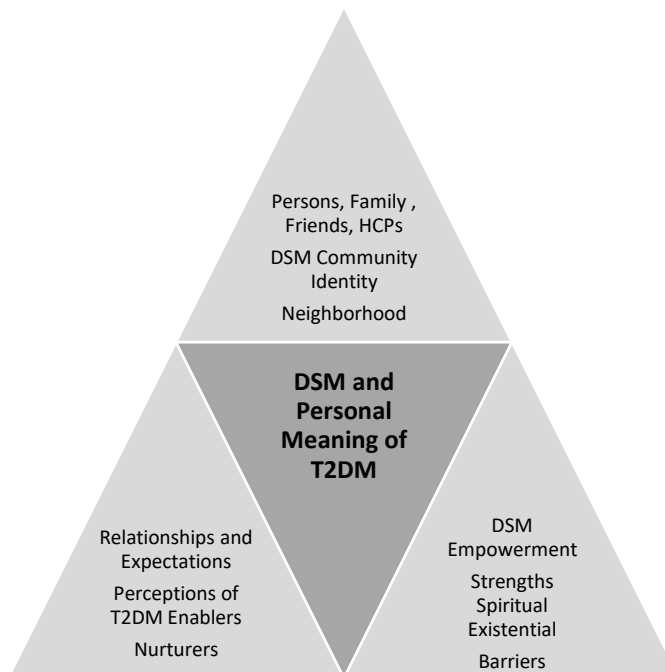
And to my beloved children, Stefan and Amelia, who didn't really understand why I spent so much time talking about diabetes and Native people – someday they will.

Dissemination Plan

The primary description of this dissertation work will be submitted to *The Diabetes Educator* as a manuscript for review and consideration for publication.

APPENDICES

Appendix A – PEN-3 Cultural Model



Selected Domains of the PEN-3 Model (Airhihenbuwa, 1990)

The PEN-3 model situates the study using a lens of strength aimed at understanding family and community connectedness within the unique culture. These meanings have important implications for the individual in how they may navigate health challenges associated with T2DM. Thus, it allows for contextual variation in health perspectives, beliefs, and values. The PEN 3 model focuses on the positive aspects in the context of self-managing chronic illness.

Appendix B – Interview Guide

Specific Aim #1 To explore perceptions of T2DM (affects, influences, and barriers) among Eastern Woodlands Tribal people and how they relate to their understandings of the cause and treatment approaches to the disease.

Conceptual Area	Main Question	Possible Probes
Personal Meaning of Illness	Before your diagnosis of T2DM, what did you know about the disease?	How did you come to know you had T2DM? What have you been told to do to manage T2DM? What have you found to be helpful to manage T2DM, what gets in the way?

Specific Aim #2 To describe how family and/or friends, and community intersect with T2DM management.

Conceptual Area	Main Question	Possible Probes
Relationships and Expectations	Tell me a bit about who else in your family and/or friends helps with the management of T2DM?	Can you tell me more?
a. Persons	Who are the people most important to you?	
b. Extended Family	How do those closest to you feel about your T2DM diagnosis?	How do others closest to you understand your T2DM?
c. Community	Tell me about how your community supports you with the management of T2DM?	

Specific Aim #3 To describe HCP relationships in managing T2DM.

Conceptual Area	Main Question	Possible Probes
Relationships and Expectations	Tell me about your relationship with your HCP, how does s/he support you in the T2DM management?	Is there anything that you wish was different in your relationship with your HCP?
a. Perceptions	What have you found to be helpful to manage T2DM?	

b. Enablers	How would you describe others outside of your family and friends that help you?	
c. Nurturers	Can you describe what you believe nurtures you?	

Specific Aim #4 To determine resources and strategies from the participants' perspectives that would help DSM within their community.

Conceptual Area	Main Question	Possible Probes
The Community	What other resources and/or supports would help you manage T2DM?	Can you tell me more about this?
a. Positive	What do you think is most helpful in your community for help in managing T2DM?	
a. Existential	What has remained the same for you since your diagnosis of T2DM?	Can you tell me more about this?
b. Negative	Can you describe what you think gets in the way of maintaining health with type 2 diabetes?	

Appendix C – Qualitative Data Management and Analysis Concepts

Qualitative Descriptive Data¹ Management	Qualitative Descriptive Data Analysis¹
Researcher Reflexivity (Sensitivity and Respect) Openness to Emerging Questions Early Transcription of Interview Results Interview Descriptive Summaries Audio-Tape Verifications Field Note Observations Documented Data Management according to Ose (2016) ²	Coding Chunks of Data ² Identifying Similar Themes (Phrases, Beliefs, Behaviors) Identifying Commonalities Iterative Confirmations Descriptive Accuracy Meaning of Phenomenon

¹Willis, et al. (2016).

Data Management Ten (10) Step Method²	
1. Collect the data	Recording of interviews (2 recorder devices) Accuracy of information depends on good quality of sound.
2. Transcribe the audio files	Convention in transcribing with I: for interviewer and R: for interviewee No line breaks inside quotes Use of a colon only as a separator between quotes from I: and R: Each interview is saved in a separate Word file with case number
3. Transfer text from Word to Excel	Copy interview text from Word into Excel using the first left column (with no headings). See Ose (2016) for Excel instructions to create data tab; text to columns; to create separate columns as described. Use a new sheet (1,2, 3) for each interview.
4. Prepare Excel document for coding	Bold all interview questions in column B to separate interview questions from respondent answers.
5. Code in Excel	Flat coding at this stage. Detail is up to researcher. If one answer contains many codes; copy answer and assign all codes. Make a separate sheet with Codes and keep a list of all codes used. The separate sheets for each interview are kept for the entire coding process.

	<p>Collect Demographics or Presentation in a separate sheet to collect information on how participants describe themselves. Most coding will occur during the first few interviews.</p> <p>Keep a list and print the list for easier access for which code to assign in subsequent interviews.</p> <p>Go back and forth to determine if coding is correct or needs amendment. <i>*Note: Using the PEN-3 Model may provide beginning codes in this study.</i></p>
6. Prepare the coded interviews for sorting	<p>Define respondents</p> <p>Keep track of the sequence in each interview.</p> <p>Combine all interview in the same sheet</p> <p>Link the information in the columns to the quotes.</p> <p>Include the code list in the same sheet as the coded interviews</p>
7. Sort the data	Sort data by columns (G, H, A, B, C) in that order. Use 'data', 'sort', 'add levels'.
8. Transfer quotes and references from Excel to Word	Use a blank Word document to transfer Excel data from column F. all other columns are omitted at this stage.
9. Sort the text into a logical structure based on the coding	Create headings. (view, outline, show level 2). Drag and drop headings and the text will follow. Change and rearranged data as desired. When satisfied with the structure of the text prepare for analysis.
10. Analyze the data	Follow qualitative descriptive methods for thematic analysis of text <i>*using the PEN-3 model to determine thematic content.</i>

²Ose (2016, p.3)