THE ROLE OF SOCIAL SUPPORT IN THE MANAGEMENT OF TYPE 2 DIABETES MELLITUS AMONG AMERICAN INDIANS:
A QUALITATIVE STUDY

Izza Atiqa Ishak, MPH, Melissa L. Walls, PhD, and Benjamin D. Aronson, PharmD, PhD

Abstract: The purpose of this study is to gain insights of American Indian (AI) communities on the role of social support in type 2 diabetes (T2D) management. Social support is a means of enhancing social and personal resources that can address underlying stressors that contribute to T2D inequities and represents a potential channel of intervention to improve management of T2D in these communities. This community-based participatory research included AI adults from the Bois Forte and Lac Courte Oreilles Bands of Ojibwe and consisted of focus groups that were conducted with people with T2D, social support persons, and service providers. Overall findings underscore the importance of social support in T2D management, especially in providing emotional support, fulfilling an appraisal function, and enabling positive health behaviors. It is also important for policies and practices to consider the social and cultural contexts, particularly the socio-historical context of life within AI communities that has inevitably shaped certain mindsets that may present barriers to care-seeking and optimal T2D management. These findings can inform interventions related to T2D management, especially in incorporating social support and complementing community strengths in achieving a broader goal of reducing diabetes inequities in AI communities.

INTRODUCTION

The prevalence of type 2 diabetes mellitus (T2D) in American Indian (AI) communities represents a significant health inequity, with AIs and Alaska Natives (ANs) having age-adjusted diabetes prevalence rates more than double those of the general U.S. population (Centers for Disease Control and Prevention, 2018). Diabetes is also a major cause of morbidity and a top cause of death for American Indians and Alaska Natives (AI/ANs; U.S. Department of Health and Human Services, 2014). One of the factors thought to contribute to increased rates of diabetes and
related complications among AI people is the differential exposure to stress (Turner, 2013; Wheaton et al, 2013). Stress process theories directly connect exposure to stressors to worse mental and physical health outcomes (Pearlin et al., 1981; Walters & Simoni, 2002). It has been shown that stressors negatively impact health behaviors and have also been associated with poorer glycemic control, obesity, and insulin resistance for patients with diabetes (Aikens & Mayes, 1997; Jiang et al. 2008).

Such theories suggest that health behavior in disease management can be mediated through two components: firstly, through addressing stressors, and secondly, through capitalizing on social and personal resources (i.e., coping resources and responses; Pearlin et al., 1981; Umberson et al., 2010). Specific to the AI/AN population, relationships between chronic to discrete stressors and mental and behavioral health outcomes have been documented, underscoring the importance of reducing stress exposure and identifying coping resources as a mechanism of improving health outcomes in people with T2D (Walls et al., 2017). One such mechanism is through enhancing social support. While there is no consensus in the literature on the definition of social support, Shumaker and Brownell define social support as “an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient” (1984, pp.11). It is a perception that one is valued and provided with help through various types of interactions, both informal (family members, friends, and peers) and formal (health care professionals, organizations; Strom & Egede, 2012). Social support can be positive or negative (Strom & Egede, 2012; Van Dam et al., 2005), although the term “social support” is usually associated with a positive influence (Van Dam et al., 2005), in contrast to “social pressure,” which often implies the inhibition of a wanted behavior (Wills & Vaughan, 1989).

Social support can be conceptualized as a component of social ties, which has been associated with health outcomes in many areas (Umberson et al., 2010). While the structural component of social ties comprises measures of social integration and social networks, the content component of social ties is reflected in measures of social support and stress (Umberson et al, 2010) and forms the focus of this study. It has been postulated that social support impacts health outcomes by facilitating self-care behaviors and coping mechanisms, as well as through physiological processes such as a reduction in blood pressure and stress hormones (Umberson et al., 2010). In the management of T2D, social support provided by one’s social networks may be a determinant of patient self-management and diabetes outcomes (Van Dam et al., 2005), and in one study, support from family and friends was shown to be positively associated with glucose self-
monitoring and healthy eating (Rosland et al., 2008). In another systematic review, higher levels of social support were also associated with positive psychosocial outcomes and behavioral modifications (Strom & Egede, 2012).

Specific to Indigenous communities, studies suggest that social context influences social support and, in turn, disease experiences (Eppele et al., 2003). Social context includes historical and contemporary stressors that contribute to AI health outcomes, disparities, and access to care (Gone et al., 2019; Elm et al., 2019; Walls & Whitbeck, 2012). Central to this is the concept of historical trauma; the resulting effects include unresolved grief and loss, survivor guilt, psychic numbing, fear, anger, and other symptoms (Whitbeck et al., 2004), which combine with direct, contemporary stressors to affect health outcomes (Balestrery, 2016; Gonzales et al., 2018; Kading et al., 2015). Yet, social context also includes culture as a protective factor; for instance, culture can influence social support mechanisms through the construction of different family units and expectations of support among social networks (Eppele et al., 2003). Factors such as the close-knit nature of often small, rural AI communities, large extended family kinship networks, and Indigenous cultural notions of belongingness may buffer the impact of stressors on health (Hill, 2006). These stress-mediating effects are also observed in the management of T2D; for example, active support by family members is associated with positive clinical measures of metabolic control for individuals with T2D (Eppele et al., 2003).

Despite the importance of social support on diabetes outcomes among non-Native populations, the existing literature provides only a limited understanding of how social support can enhance management of T2D in AI communities where inequities persist. Therefore, the purpose of this study is to investigate the role of social support in the management of T2D among AI adults from two Ojibwe tribal communities. Findings from the study can inform future efforts of enhancing social and personal resources that can buffer underlying stressors contributing to T2D inequities in these communities, thus supporting the objective of exploring social support as a potential channel of intervention to improve management of T2D.

**RESEARCH DESIGN**

**Study Design**

This study utilized focus group data from a community-based participatory research project, the Mino Giizhigad (A Good Day) Study, conducted as a collaboration between the Bois
Forte and Lac Courte Oreilles Bands of Ojibwe and university-based investigators. The purpose of the overall study was to identify and describe the impact of mental and behavioral health factors on diabetes treatment and outcomes among Ojibwe adults with T2D. Tribal resolutions from both communities were obtained prior to submission of the application for funding. The project began with community feasts and forums to discuss the study goals, obtain community feedback, and establish Community Research Councils (CRC). CRC and university team members were active participants in the entire research process, from methodological planning to final data collection and analysis. The University of Minnesota and Indian Health Service National Institutional Review Boards reviewed and approved the methodology included in this study.

**Focus Group Methodology**

Focus groups were chosen for qualitative inquiry to generate data from a broad range of community members resulting from interactions between participants (Krueger, 2014). Focus groups questions were developed in partnership with the CRCs, and groups were led by two CRC members who were trained as focus group moderators. These moderators followed a questioning route on perceptions of T2D and T2D management, the impact of non-physical health factors on diabetes care, and coping strategies, including the role of social support person(s). Examples of questions used in the focus group questioning route are described in the Appendix (Table A1). All focus groups were audio-recorded and transcribed verbatim. Focus group discussions ranged in length from 53-84 minutes and 25-73 minutes for the Lac Courte Oreilles and Bois Forte groups, respectively.

**Recruitment/Participants**

Purposive sampling was used to recruit participants for six separate focus groups: 1) two groups consisting of individuals living with T2D, 2) two groups of “informal” service providers, which includes family members and other supportive community members who care for someone living with T2D, and 3) two groups consisting of formal service providers, including medical doctors, dentists, nurses, drug/alcohol counselors, mental health practitioners, and other community-based service providers. Focus group moderators trained in human subjects research ethics worked in collaboration with local clinics and CRC teams to identify community members who matched the criteria for inclusion in each of the three groups. They used study brochures and recruitment scripts to approach potential participants by phone, email, or in-person to share
information about the study, its goals, and invite them to participate in focus groups. Moderators read informed consent documents aloud and secured signed consent forms from all participants immediately prior to facilitating group discussions. The recruitment goal was 8-10 individuals per group. Overall, there were \( N = 34 \) participants (23 females, 11 males) from Bois Forte, and \( N = 61 \) (39 females, 22 males) from Lac Courte Oreilles (total \( N = 95 \) across both sites and all groups). The number of participants by focus groups is summarized in Table A2 in the Appendix.

**Data Analysis**

In conducting a data analysis of the focus group transcripts, we used a general inductive approach guided by a set of research questions (Thomas, 2006). This seeks to allow research findings to emerge from recurring and pertinent themes in the data, specifically through three aims – summarizing data into a condensed format, drawing connections between research objectives and summary findings, and developing a framework for themes (Thomas, 2006). Central to the analysis are two research questions: 1) how does social support impact the management of T2D in AI communities, and 2) how can social support interventions address the underlying stressors that contribute to T2D inequities in AI communities? These are expanded into sub-questions or objectives to further guide the analysis process. The research questions and objectives are summarized in Table A3 in the Appendix.

Transcripts were uploaded to NVivo 12 for data management and analysis and analyzed by a single coder. An initial reading was first conducted to document repeated ideas and important quotes, which were organized into a list of categories. This was followed by a first round of coding to identify specific categories that were relevant to research objectives, guided by the initial codebook. Subsequently, a second round of coding was conducted to streamline the categories into a framework. Several strategies were employed to enhance trustworthiness of the analysis. Firstly, discussion with co-authors with respect to the coding, organization of categories, and identification of emerging themes was conducted to check for the representativeness of the data as a whole (Shenton, 2004; Elo et al., 2014). This involved the co-authors carefully following up on the analysis process and categorization of themes, following the initial analysis by the lead author. Secondly, methods of reflexivity were employed to increase rigor of research (Engward & Davis, 2015). These include considering reflexivity in the analysis of data (Engward & Davis, 2015) and employing methodological reflexivity through having regular dialogue with the research team during the developing stage of analysis to reduce potential bias and check for re-interpretation by
the researcher (Walsh, 2003). This was supplemented by discussions with the CRC members at the later stage of analysis, to seek their inputs and verify the representativeness of the findings. Memos were also used to document coder’s observations and interpretation of the data throughout the analysis process.

The analysis generated a total of 520 initial codes, which were grouped into 93 broad categories guided by the research questions. Through continuing revision of categories to reduce overlap and redundancy among categories (Thomas, 2006), these broad categories were further distilled into four summary themes, with corresponding sub-themes.

**RESULTS**

Overall, the four themes that emerged from analysis of the transcripts are as follows: 1) perception of social support, 2) functions of social support, 3) social and cultural contexts of Indigenous communities, and 4) considerations in implementing social support components in T2D management. A summary of the four themes and sub-themes is included in Table A4 in the Appendix.

**Perception of Social Support**

The first theme that forms a baseline to the understanding of the role of social support in T2D management is the participants’ perception of social support, particularly in reference to the importance of social support in T2D management, the attitudes towards social support, as well as the sources of social support provision. Participants deemed **social support as important in the management of a chronic disease like T2D**; this was a common theme among individuals with T2D, social support persons, and service providers. It was also perceived as important especially in times of crisis, such as during a hypoglycemic episode.

In terms of the **attitudes towards social support**, participants from both the social support and service provider groups also exhibited a keenness to offer social support, even if they were not currently caregivers for someone with T2D. A male participant in the social support group shared,

> In a way, it make me feel good, you know, that will help people just in general, you know, and I think it makes a person who is diabetic, you know, grateful for the help that you are doing for them, you know, so they, so they don’t have to, how would you say that, lift all the weight by themselves, where say, you know, they can sort
of rely on people to get stuff done for them, you know, and that makes both parties happy, I guess.

Another sub-theme concerned the uptake of social support. Despite the role that social support persons played in increasing understanding of T2D, individuals with T2D cited the importance of having basic knowledge of T2D. Uptake of social support was also influenced by the reaction of a person with T2D towards the provision of social support, as what a caregiver commented,

He kind of got mad at me at first. I said, ‘you wouldn’t do this,’ I said, ‘because you’re not paying attention to your diabetes,’ I said. ‘You’re not taking care of yourself.’ I said, and you can get mad at me if you want, I said, this is what I’m going to do for you, I told him.

As for the sources of social support provision, participants cited a variety of sources, namely family members, health care providers, and spirituality, with several participants in the T2D group describing a spiritual affinity that provide support in the absence of physical loved ones, and how they turned to clergy for support. For many participants, family was cited as a primary source of social support. Besides family, the wider community also formed a key resource of social support, especially in the form of social connectedness. Participants highlighted several ways in which community is integral in supporting T2D management; this included having diabetes support groups and engaging with other community members in common facilities and community gatherings.

Functions of Social Support

Social support was understood to fulfill several functions, such as in providing emotional support. Social support persons also played an integral role in providing instrumental support, specifically by helping the patient with different components of T2D. These included components such as meal planning, cooking, reminding to take medications, and attending appointments. Some described a more generic form of help, such as by providing administrative and logistical support or assisting with everyday tasks. A female participant with T2D shared how support from her husband was important in such a time,
But you do need to share with them, because what if you, well I don’t know where you are on your diabetes, but what if you went into a low sugar, like I did when we were coming up the freeway, and they wouldn’t have a clue what to do for you. My husband knew that I needed sugar and that’s all he knew.

Besides the functions of providing emotional and instrumental support, some patients cited the importance of social support person(s) acting as role models and providing positive reinforcement. An example of this was given by a male participant in the T2D group,

I don’t know, I think the positive influence like, like somebody telling you like if you go to the doctor, like for a checkup, and they tell you, well you’re doing a good job that your, your A1C hasn’t gone up, or you’re really working hard at doing, just keep doing what you’re doing. Some positive reinforcement to keep you motivated to keep going, keep trying to control your disease.

There was also a notion of social support persons playing an enabling role, such as in helping individuals with T2D take greater ownership of their health and be more open to seeking help. A caregiver spoke of her experiences with her mother, who has T2D,

She still doesn’t ask for all the help that she could actually use and need, but instead I am there to ask for her for that help, so I am kind of like, I don’t know, enabling. But I always tell her, “Mother, you need to do this, you know, don’t be afraid.

As for the approaches in providing social support, there was a conflict expressed by social support persons in between taking a soft approach and being strict with the family members they are supporting. Often, the former is equated with an expression of love, but some realized that the latter approach might be more beneficial to patients. This was more pronounced among family members, as illustrated by a female participant in the social support group, who said,

I said, ‘Love you to death son, but I’m not coming here anymore.’ You know, you can, you can stop this from happening just by taking your medication and eating the right foods, and I will not follow you to the hospital anymore. I love you but I can’t do it, and he started doing it again, so, that’s, I think that’s tough.
Social and Cultural Contexts of Indigenous Communities

The third theme that arose from the discussions related to the social and cultural contexts that are unique to Indigenous communities; these are framed into two main dimensions: 1) **barriers to optimal T2D management** and 2) **strengths relating to the unique social and cultural contexts** that can enhance T2D management.

Firstly, several mindsets were observed in the participants’ words that inhibited social support and T2D self-management. These mindsets reflect underlying **illness beliefs** regarding the disease. Among the most prevalent of these illness beliefs was that of **denial**. Denial was observed at various stages of the disease, such as at the time of diagnosis, and was commonly cited by participants as one of the barriers to care seeking and optimal T2D management. This was sometimes associated with the challenge of sharing the diagnosis with family members. Denial was manifested in a lack of seriousness towards T2D management, often until a crisis occurs. On the other hand, having acceptance as opposed to being in denial resulted in positive outcomes, and service providers cited improvement in clinical indicators when patients are able to accept their diagnosis. Participants also recognized that acceptance is a key precursor to behavior change and a greater sense of perceived control. A female social support person described the value of acceptance in this way,

> I think once they, once they learn to accept the fact that they’ve got it and it’s never going to be cured, I think their attitude changes towards, you know, they start accepting the fact, that I got to eat different, and I’ve got to start exercising, and I’ve got to check my blood sugar on a regular basis, and that kind of thing.

Another recurring theme found was the **belief of not wanting to be a burden**. Participants in the T2D group frequently described that they found it challenging to ask for help, even from family members, and even at times of crises. This raises the question of the complexity of social support. At a broader level, this belief can impede care-seeking behavior, such as attending medical appointments regularly.

Other illness beliefs that were found included shame or embarrassment with a T2D diagnosis, and fear and hopelessness or perceived lack of control over the condition. On the extreme end of the spectrum, there were some patients who expressed a fatalistic mindset and how it resulted in a reluctance to take a more proactive role in T2D management. Such beliefs may be
attributed to the behaviors shaped by the socio-historical context of AI communities that shape coping behaviors in response to challenging life events such as managing T2D.

It is also important to consider the unique social and cultural contexts of AI communities that interact with social support mechanisms to influence health behavior. Central to this theme is the concept of cultural identity, often mentioned as a strength in addressing T2D. Participants identified benefits of an Indigenous lifestyle, perceiving that traditional diets are healthier than modern alternatives. A participant from the T2D group shared, for example, how herbal teas could be beneficial in T2D management,

And I think about that, you know, some of the old ways used to be, you know, I don’t know how prevalent diabetes was before we started living in houses and driving cars and that sort of thing, but part of it is that, but I, but like I started doing the birch leaf tea. I know a few other things that you can do, you can do too that used to be done all the time. Always, ‘cause they were always out there, and they would take those teas, and they would drink those teas. Nobody hardly drinks those teas anymore. You drink black tea or green tea. I mean, you know, how many people these days drink wintergreen tea?

There was also a notion that AI communities tend to be more physically active, due to the preference for walking, as well as their direct involvement in farming or growing produce that had a two-fold effect of increasing physical activity and connecting them to their cultural identity. Expounding on the benefits of the Indigenous lifestyle, a service provider also made reference to hunting and gathering, suggesting that the rise of T2D could be attributed to a decline in such traditional activities,

Look at the major population, has been in and amongst all that, not hunting and gathering for thousands of years. They’ve been farming stuff. What does that do to us? So diet and exercise. I mean, you know, we no longer have to run our meals down. Or run over and steal it from somebody else and then run from them.

Furthermore, participants expressed optimism for the ability that Indigenous culture had to overcome the challenges associated with T2D management. This was echoed, for instance, in the remarks of a service provider,
As far as cultural community, I don’t think there are any barriers, as far as helping getting diabetes under control. I think as a native people, we’re more or less active for, as far as our culture, culture goes, every part of the year we have a certain season for, you know, things that we’re always doing something.

Alongside cultural identity, *family* was another key factor related to the sociocultural context of AI communities that play a role in social support. Participants in this study highlighted specific functions that family had in T2D management. Many expressed a desire for family members to be actively involved in T2D management and expected family members to have knowledge on T2D. Family members, both immediate and extended, were described as a great *motivation* to manage T2D. Family was also cited as the first factor that came to mind upon knowledge of diagnosis; this contributed to its role as a motivation in T2D management. It was also deemed crucial at times of crisis, such as during a hypoglycemic episode. A female participant with T2D poignantly expressed the centrality of family as a motivating factor,

I just want to say, ah, the hell with it sometimes. Then I get up and the first thing I see is my grandkids’ pictures on the wall (names them). Then I think about them and what they would think. Look at how devastated they were when they lost their papa. They were all just devastated by it even though they knew he was dying from cancer. They still had a hard time. And I think about that and if I should just give up, they’ll go through the same thing again. Then I tried to bring myself up and think of good times and think of my grandkids and I still need to teach them more things.

Moreover, a pertinent role that family played as a mechanism of social support was that of providing care. This was depicted in various types of relationships, such as that between parents and children. T2D was said to influence care provision when the disease prevented patients from taking care of their family members, such as in managing day-to-day affairs. Disappointment was sometimes expressed when having T2D limited this ability. At times, fulfilling this role took priority over taking care of oneself. A male participant with T2D described the conflict that he experiences when his familial obligations impeded his ability to care for himself,

You know, so for me, that’s the, that’s the main thing for me is just the, try and get into a routine where you have to take care of yourself. You know, sometimes you
have to put other things aside and take care of yourself when you need to, and you know, I’ve always used that as excuse, that oh my, no my kids come first and I need to take care of my kids first, and stuff like this, but no, no I really can’t use that as an excuse anymore, because my kids are all grown up now. So, now then, it all falls back onto me, now, having to take care of myself.

Provision of care was also apparent in the relationships between grandparents and grandchildren, sometimes alluding to a parenting role adopted by grandparents. This was suggestive of the influence that inter-generational factors can have on familial social support. A female participant in the T2D group shared,

Because then, I’m trying to raise 5 grandchildren besides and take care of them and take care of myself and then I always think, ooh, if I get worse, what’s gonna happen to my grandchildren?

As such, provision of care was a key consideration of the familial dimension of social support. While previous examples demonstrated how family, as a mechanism of social support, support positive behaviors in T2D management, the later examples suggest that it can also be inhibitive, when familial expectations of care provision supersede one’s ability to prioritize self-management of T2D.

Expectations of providing social support within families also varied by gender, with women perceived as having a greater role in care provision. Although this was an accepted norm, some expressed a need for greater male involvement. A participant from the service provider group cited his observation,

I mean, she addresses that somewhat, culturally, you know, generally speaking, they’re, the female takes care of the family, okay… Alright, when we diagnose a man with diabetes, we try very hard to get, to get the female in there to help take, to help him take care of him. You know, we diagnose a woman with diabetes, very seldom do we get that man in there…

Other service providers echoed such observations, by commenting on how, for instance, women speak for their husbands and demonstrate greater attention during medical appointments, while such was not observed when women are the patients. These experiences highlighted a
concern that women may be receiving lesser support than men in the management of T2D. Another service provider expressed his thoughts on how men can have a greater involvement in the care of themselves, as well as for their loved ones,

And you know, I think that culturally speaking, that if we can make that impact on the males when they’re younger, like this program that we’re trying to get going now, okay. That it’s, that these are things that they need to be responsible for… And so, culturally speaking, we need to make the males more aware that, you know, that it’s okay to take care of yourself. And number two, it’s okay to take care of someone else.

These comments suggest that there is a role for greater gender role flexibility in ensuring that women receive greater support in the management of T2D. A greater level of male involvement in their own care can also reduce the pressure of care provision that women may have.

**Considerations in Implementing Social Support Components in T2D Management**

Participants also conveyed several considerations in implementing social support components in T2D management. Stress constituted a substantial part of the discussion and alluded to the **importance of addressing various components of stress** in developing social support interventions. Participants in all three groups described various components of T2D management as stressful; these included having to keep up with medications, as well as having to manage other co-existing chronic conditions. Stress was also described in care provision, such as from a social support person who spoke regarding his family member who has T2D,

His stress level, his stress level hasn't been all that much lately. He, the only way, the only way he gets like really stressed is when he’s got to pick up his little kids from grandma, or his kids, now if his kids need help or something, and he can’t do it, then he gets kind of, a little bit stressed out about it, but, he’s been doing, he’s been hanging in there pretty good with it.

Various stressors in T2D management were also described, such as family, finances, home environment, and unemployment. A pertinent stressor that was repeatedly discussed was having multiple responsibilities, compounded by financial difficulties. Stress was attributed to not having
enough finances to manage day-to-day aspects, such as groceries. A female participant in the T2D group described her daily worries,

> I think it’s just the worry about, about doing day to day things like, sometimes you’re running kind of low on money, and you’re always thinking, well now where am I going to get my groceries, where am I going to get my gas. You know, just daily little things that you worry about, like what’s going to happen to me today, what am I going to be doing today, where am I going to be going?

In view of these stressors, participants in the service provider groups related the importance of coping strategies to manage stress and improve T2D management. Participants with T2D cited several coping strategies, such as exercise, creative expression, and staying busy. Additionally, the presence of a support system was paramount in addressing various stressors. This was echoed by the comment of a female service provider,

> And, you can’t eliminate stress, but you need to help people and help yourself deal with it in a different way. Or, find a good and a bad somehow, and make change there, but that’s really hard to see in the moment of this black cloud that surrounds you as you’re walking around, you know. A support system would come in very handy there.

In addition to addressing these stressors, having an understanding of how participants perceived the integration of social support in T2D management is essential in developing interventions. Participants raised the need to consider the emotional toll on social support persons, namely caregiver stress. Social support persons alluded to a negative impact on themselves when they observed their loved ones with T2D lacking personal responsibility toward managing T2D, such as not adhering to treatment components despite their advice. Moreover, providing social support was also perceived to be more challenging or stressful if patients had multiple comorbidities. At the same time, participants also recognized the positive impact on social support persons. This included having a greater awareness of T2D, which can be a motivation to adopt healthier behaviors in preventing T2D.

Participants also described the idea of balance in T2D management and how it was an important consideration in the provision of social support. Balance was described in several ways, such as the balance between physical and mental or emotional health or as the balance between
taking a serious and light-hearted approach in encouraging patients to adopt healthier behaviors. A service provider summarized this point by sharing her perspective on providing balanced advice,

I think it’s important to not take anything away from someone, especially in the beginning. And to be the accepting, in other words to say, you know, if you drink your body will work with it this way while when you have diabetes, so I don’t want to sanction and say, you know, go out there and drink because it’s just fine, but I don’t want to say take away your whole social activity, but rather, ok, if you have a drink, your body is going to interpret it as sugar. This interpretation is going to be wrong and you could get into trouble with low sugar, so always eat if you’re going to drink. Something simple I could say.

**Timing** was also a consideration in the provision of social support. The time of diagnosis was frequently cited as the most stressful due to the multiple routine checks involved, information overload, and a perceived lack of control. This suggests the role that social support can play at this time, and how this can translate into early care-seeking behavior.

Finally, while participants described the strengths of an Indigenous lifestyle in supporting social connectedness and T2D management, considering the *challenges associated with these social and cultural aspects* is also important for a holistic understanding of an Indigenous lifestyle. Central to the concept of social connectedness was the role of food, which is often associated with social activity. Some participants described the challenges of balancing social expectations to enjoin community activities where food played a key role and the need to adhere to dietary guidelines to promote diabetes control. This was compounded by the limited healthy food options available at such events, as described by a participant who faced such challenges,

The other phenomenon, as far as going to potlucks and not being able to find your perfect food is going to potlucks and have people looking at you and saying, ‘I am sorry, we don’t have anything for you to eat.’ I have had that happen and it’s like, I think I can eat. Just because I got diabetes doesn’t mean that I haven’t got food.

Overall, participants describe the importance of addressing various stressors in T2D management, considering caregiver stress, achieving balance, considering appropriate timing, and looking into the challenges associated with social and cultural components of an Indigenous lifestyle – so as to support T2D management in the community.
DISCUSSION

This study explores the perspectives of AI communities on the role of social support in T2D management and presents ideas on how social support can address underlying stressors that contribute to T2D inequities, as well as provides a potential channel of intervention to improve T2D management in these communities. The findings encompass ideas relating to four dimensions of social support, namely 1) perception of social support, 2) functions of social support, 3) context of social support, and 4) implementation of social support interventions. These reinforce previous works on the dimensions of social support, while introducing several new ideas.

The first step to understanding how social support can be explored as a means of intervention in improving health outcomes is to understand the perceptions on the sources of social support and the type of social support being provided (House et al., 1988). These dimensions are depicted in the participants’ understanding of the meaning of social support. The sources of social support can range from those in one’s informal network (for example, family, friends, coworkers, supervisors) and in more formal networks (for example, health care professionals, human service workers; Heaney & Israel, 2008). In this present study, participants highlighted the preponderance of informal networks as a source of social support, particularly family and community members. This reinforces Kaplan’s work on social support and health that describes how relationships are key sources of support (Kaplan et al., 1977). Another key factor to consider is the content of social support; this is related to the perceptions of support recipients, rather than the objective behaviors (Wethington & Kessler, 1986). Participants’ description of social support as important in T2D management, as well as their keenness to offer social support, suggest the potential that interventions comprising of social support components can have in enhancing T2D management for individuals with T2D.

Although the exact mechanisms of how social support affects health outcomes are not known, research suggests that some potential mechanisms include stress-buffering effects, changing affective states, increasing self-efficacy, and influencing change in negative health behaviors (DiMatteo, 2004). House et al. (1988) characterize these potential mechanisms of social support into four main components: 1) emotional support, 2) instrumental support, 3) informational support, and 4) appraisal support. The functions of social support described by participants affirm these mechanisms, especially the emotional and appraisal function of social support. In addition, participants describe mechanisms such as positive reinforcement and an enabling role that social support can play. Understanding these mechanisms of social support is
important in developing interventions and building on the social support functions that are already present in the community.

Another aspect to consider is the social and cultural contexts unique to Indigenous communities and how this can influence social support. Alongside the key dimensions of support discussed previously (meaning and function), it is also important to consider the range of contextual factors that may affect its form and occurrence (Shumaker & Brownell, 1984). These contextual factors include the characteristics of participants and environmental characteristics (Shumaker & Brownell, 1984). Participants’ perspectives on the social and cultural contexts can be understood in two dimensions, firstly, contextual factors that represent barriers to optimal T2D management, and secondly, strengths relating to the unique social and cultural contexts that can enhance T2D management.

Barriers to optimal T2D management can be linked to specific socio-historical factors that influence illness beliefs among AI individuals, therefore influencing health outcomes. Studies of disease “explanatory models (EM),” which refer to how patients conceptualize illnesses and seek treatment, find that these EMs are impacted by cultural factors – factors that can either support or inhibit positive health behavior (Henderson & Henderson, 2002). Specific to AI communities, historical trauma experienced by AIs have been shown to influence the construction of illness narratives. Traumatic experiences, alongside the influence of neocolonialism and oppression, have been associated with the onset of T2D, with AI individuals describing how experiences such as domestic violence and substance abuse issues result in feelings of powerlessness and guilt (Ferreira, 2006). Hill (2006) describes the importance of the balance between an individual and the environment, and how lived experiences can influence coping behavior. These can result in survival skills such as learned helplessness, denial, and passive-aggressive behaviors (Tafoya & Del Vecchio, 2005) – themes that were conveyed directly and indirectly in this study. These shape mindsets of denial and a reluctance to ask for help, thus influencing EMs of T2D that can manifest in delayed care seeking (Henderson, 2010). It is crucial to consider these mindsets, especially where they can pose a challenge to the provision of social support. For example, reluctance to ask for help may impede the uptake of social support even when widely available. The understanding of the socio-historical context is thus important in identifying risk and protective factors specific to the AI community so as to develop culturally tailored interventions (Whitbeck, 2006), address gaps in social support provision, and leverage on the strengths of the community in the efforts to improve T2D management.
At the same time, the unique social and cultural contexts of AI communities also present several strengths that can be considered in incorporating social support components in T2D management. A salient point is the importance of a sense of belonging in AI communities; this is influenced by cultural identity, traditional practices, and the value of community. Hill (2006) describes the AI worldview and the central role of relatedness and connectedness in health outcomes, relating to having a sense of belonging that stems from understanding the individual and community’s place within the tribe. Factors that impact the relatedness/belonging and health outcomes include cultural identity, traditional practices, community, and family values and beliefs (Hill, 2006) – themes that were also found in the participants’ responses. Thus, engagement with cultural identity, traditional practices, and community has great implications in the management of T2D and should be considered as a scaffold for social support interventions.

Another sociocultural context pertinent to the role of social support in T2D self-management in AI communities is the context of family. Participants in this present study relate the fact that family constituted a large aspect of social support provision, with family having specific functions in the management of T2D. The family is widely recognized as an important social context for health behavior change, due to its fundamental role in shaping child and adolescent behaviors and the intensity and longevity of interactions with family members that have the potential to effect change across the life course (Okechukwu et al., 2014). As such, it presents a unique channel of intervention in T2D management. Specific to AI communities, previous literature has shown a preference for family support in help seeking (Aronson et al., 2016; Walls et al., 2006), and in the context of T2D, engaging family members has also been shown to be feasible, acceptable, and impactful (Chambers et al., 2015). Family constitutes a central aspect of Indigenous lifestyle and identity and plays an important role in T2D management. This includes being a motivation for improving self-management. Conversely, the absence of familial support has been cited as a source of stress for individuals with T2D (Elm et al., 2019). This stems from family members lacking understanding about the disease, resulting in disappointment and frustration among individuals with T2D (Elm et al., 2019). It is thus unsurprising that participants convey a desire for family members to have knowledge on T2D, both as a means of providing support and a preventive measure for the family members themselves.

Related to family are the roles that family members play in the provision of care. Familial obligations and interdependence are core values in tribal communities (Goins et al., 2011), and providing care for the family, especially dependent members, is deemed important (Baldridge,
Moreover, the extended family holds particular significance for AIs and is seen as a protective buffer that provides social, emotional, spiritual, and material support to each other (Martin & Yurkovich, 2014). Such family values can be viewed as an avenue of social support when the provision of care includes supporting family members in T2D management. Yet, they can potentially also pose a challenge when patients with T2D prioritize looking after their family members over their own needs of managing T2D. The differing expectations of care provision between genders are also a consideration in familial social support; these underscore traditional gender roles in AI communities, where women play a significant part in raising families and are viewed as caretakers of children and relatives (Martin & Yurkovich, 2014). These roles extend to their old age, where playing the parts of grandmothers is an important obligation (LaFromboise et al., 1990; Bahr, 1994). While women in AI communities hold these roles in high esteem, findings from the present study suggest that a certain level of gender role flexibility can promote greater balance of social support, especially in favor of women who feel like they may not be receiving as much support as men. As such, social support interventions should consider the various dimensions of family roles, perhaps by generating discussion on how to balance these roles with one’s own self-care, as well as to facilitate greater male involvement.

Lastly, perspectives shared by participants highlight several considerations in developing social support interventions. Understanding the stressors in the management of chronic diseases such as T2D is fundamental in exploring the potential of social support interventions in mediating these stressors. While these stressors are experienced as chronic strains precipitated by discrete events, they are often developed in the contexts of prior unresolved loss and grief and can often be linked to fundamental causes such as poverty, genocide, and colonization (Elm et al., 2019). This represents multigenerational layers of trauma that predispose Indigenous people to illness through greater exposure to stress (Link & Phelan, 1995). Given the substantial evidence that stress is associated with T2D etiology and outcomes (Fisher et al., 2008; Hamer et al., 2010; Roberts et al., 2015), it is therefore crucial to understand how people with T2D perceive stress and how social support can seek to buffer these stress experiences.

Participants in the present study echo perspectives of other AI communities in earlier studies, specifically, that stressors in the context of T2D relate to chronic stressors such as financial stressors, health management, social roles, and job features (Walls et al., 2017; Elm et al., 2019). A dominant theme among these chronic stressors related to social roles, with many participants in this study sharing how having multiple responsibilities, particularly in caretaking
activities, resulted in additional stress compounded by the stress of managing a chronic disease. This augments the earlier discussion on the dimensions of family roles and how interventions should seek to address role-related stressors in order to facilitate greater self-care and enhance T2D management. In particular, interventions can consider the stress-reducing functions that social support can have (Shumaker & Brownell, 1984). This includes the specificity model of support, where social support can provide the patient with T2D with the specific resources needed related to the stressor, hence functioning as a direct coping strategy (Shumaker & Brownell, 1984). This can be relevant in addressing chronic stressors such as financial stressors and employment. As for role-related stressors, social support can function as a means of cognitive appraisal and adaptation, where social support persons promote clearer understanding of the stressor, provide coping resources, and enhance self-esteem in coping with the situation (Shumaker & Brownell, 1984). Studies in other populations have documented positive effects of social support on psychosocial outcomes, such as depression and quality of life (Bond et al., 2010; Sacco & Yanover, 2006), with one study reporting that individuals who reported having greater proximal and distal sources of social support were associated with having less depressive symptomology and better diabetes self-management (Fortmann et al., 2010). These augment the notion that social support interventions have potential in buffering such stressors, thus improving T2D self-management. Moreover, participants highlight other considerations in the implementation of social support interventions, such as the importance of considering the potential stress on social support persons in developing social support interventions. While caregiving and family can be protective, it can also impact physical and mental health (Coser et al., 2018). At the same time, caregiving offers a platform to draw upon the benefits of increased education and awareness of T2D for family members who do not have T2D. Timing is also key, and involving social support persons at earlier stages of the condition may also have multi-fold effects of preventing caregiver stress, while encouraging earlier care seeking for the patients. Finally, while the social and cultural contexts of Indigenous communities provide many avenues of promoting social connectedness and T2D management, it is also important to consider the challenges associated with these aspects, such as current gaps in integrating aspects of healthy eating into community events. This can be addressed by offering healthier eating options at community gatherings, as well as increasing education and awareness on T2D, especially through platforms that are interwoven with stories of community members – solutions that are voiced out by participants themselves in this study.
Limitations and Future Work

We acknowledge several limitations to this study. We developed the questions for focus group interviews in collaboration with CRCs; their feedback, input from the broader community, and extant prevalence data led us to focus on T2D as a significant problem. As such, many of our questions aimed to elucidate nuanced understanding of the stressors and struggles associated with T2D. A limitation to this approach is that our questions may have biased participants to focus solely on problematic aspects of T2D for the community and individuals living with the disease.

As we took a predominantly inductive approach to the data analysis, we identified a broad landscape of themes that provides an initial understanding of the role of social support in T2D management, guided by theoretical frameworks of social support constructs. We recognize that the data in this present study is extremely rich and detailed, and further analysis can reveal deeper nuances that can augment the understanding of social support, especially relating to AI communities. Given the preponderance of stress in T2D management, and the presence of historical and contemporary stressors relating to the social context of AI communities, further investigation of dimensions of stress pertaining to social support is important in future research. This includes other categories of stressors such as microaggressions and lateral oppression, which are widespread in the community (Elm et al., 2019). As such, these additional stressors should be given further inquiry especially where they may influence the provision of social support by health care providers and community members.

While social support forms the content component of social ties, future research can also seek to examine the structural component, which is the role of social integration and social networks. Such will complement the findings from this study and present a more holistic understanding of the nature of social relationships in health outcomes.

It is envisioned that the insights gained from this study can inform future social support interventions in supporting T2D management. An existing framework that social support interventions can be incorporated into is the community health worker (CHW) model, often referred to as community health representatives (CHR) in AI communities, where CHRs serve as community members who can mediate between health care systems and communities to improve the health of the population (Satterfield et al., 2002). CHW models have shown to be effective in improving T2D self-management in other underserved populations, such as by improving HbA1c levels and other clinical outcomes, as well as by increasing patient satisfaction and knowledge (DePue et al., 2013; Gary et al., 2009; Norris et al., 2006; Gary et al, 2003). In AI communities,
individuals with diabetes who were enrolled in a multi-level intervention involving CHRs have been shown to have improvements in glycosylated hemoglobin and low-density lipoprotein (Trevisi et al., 2019). While these interventions involve social support components such as patient accompaniment and home visits, future CHR interventions can expand on the social support components and investigate the effectiveness of these in improving T2D outcomes. Such interventions can incorporate the structures of social support highlighted in this study, as well as to address the barriers to care seeking and optimal T2D management. Cultural identity and strong social ties are also strengths that can be leveraged in developing interventions. These can complement the community members’ suggestions on T2D management interventions, such as the inclusion of personal narratives, social network interventions, and community-driven services.

CONCLUSION

All in all, social support has been shown to be beneficial in improving T2D management and overall outcomes. Findings from this study elucidate some of the mechanisms of social support specific to AI communities, as well as important social, cultural, and historical factors influencing social support. It is envisioned that the findings of this study can inform social support interventions related to T2D management, in seeking to achieve a broader goal of reducing diabetes inequities in AI communities.

REFERENCES


Strom, J. L., & Egede, L. E. (2012). The impact of social support on outcomes in adult patients with type 2 diabetes: A systematic review. *Current Diabetes Reports*, 12(6), 769-781. [https://doi.org/10.1007/s11892-012-0317-0](https://doi.org/10.1007/s11892-012-0317-0)


ACKNOWLEDGEMENTS

The authors would like to acknowledge the contribution of members of the Mino Giizhigad Team, including Community Research Council members: Doris Isham, Julie Yaekel-Black Elk, Tracy Martin, Sidnee Kellar, Robert Miller, Geraldine Whiteman, Peggy Connor, Michael Connor, Stan Day, Pam Hughes, Jane Villebrun, Muriel Deegan, Beverly Steel, and Ray Villebrun. The authors respectfully acknowledge commitment and participation of project team members in addition to their thoughtful review of this manuscript.

FUNDING INFORMATION

Research reported in this paper was supported by the National Institute of Mental Health under Award Number MH085852 (M. Walls, Principal Investigator). The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.
AUTHOR INFORMATION

Izza Atiqa Ishak is an MPH graduate from the Johns Hopkins Bloomberg School of Public Health in Baltimore, MD. Dr. Melissa L. Walls is an Associate Professor of American Health in the Department of International Health and Director of the Great Lakes Hub of the Center for American Indian Health at Johns Hopkins University in Duluth, MN. Dr. Benjamin D. Aronson is an Assistant Professor of Social and Administrative Pharmacy in the Department of Pharmacy Practice in the Raabe College of Pharmacy at Ohio Northern University in Ada, OH.
APPENDIX

Table A1
Examples of questions for focus groups

1. Community members living with T2D

- When did you first discover you had diabetes?
- How has your outlook on life changed, if at all, since you were diagnosed with diabetes?
- What were hardest things to change in your life?
- How do you feel about living with diabetes on a day-to-day basis?
- How, if at all, does stress impact the way you manage your diabetes?
- If you were interested in getting more information on topics such as diabetes care, mental health, and coping with stress, where would you go for help?
- Are there any barriers that would stop you from asking for help about these or other health topics?
- Overall, how do you cope with your diabetes? How do you cope with the stressors and emotional challenges in your life?
- Who, if anyone, are the significant people you rely on during challenging times?
- What types of programs or initiatives are needed to effectively address diabetes in your community?
- What role did/does the community play in your diabetes diagnosis and management?
- What are the strengths and weaknesses of your community in addressing diabetes?

2. Social support persons

- Think of the people who are close to you that are living with T2D. What are some of the challenges you see that are related to living with diabetes?
- Do these friends or family members sometimes need support managing their disease? If so, how do you support them?
- Do you think stress plays a role in how people manage their diabetes? If so, how?
- What mental health or emotional challenges have you noticed in people who have been coping long-term with diabetes?
- How has being around someone close to you with diabetes impacted your life?
- What is the best way to address diabetes in the community?
- What role can social support services (friends, family, elders) play in addressing diabetes?
- Do you think that having social support systems are an important part of diabetes treatment?

3. Service providers

- How big of a problem is T2D in this community?
- What role do you see lifestyle (for example, diet and exercise) playing in diabetes diagnosis and management?
- What, if any, mental health issues do you commonly see as a service provider in the community?
- Our project is interested in understanding diabetes management and treatment in your community. We are especially interested in knowing about ways in which non-physical health (for example, distress, depression, anxiety, substance use) and stress might impact diabetes care. How are mental health issues dealt with? How are they perceived by the broader community?

continued on next page
### Table A1 Continued

*Examples of questions for focus groups*

#### 3. Service providers

- When discussing diabetes in a clinic setting, how is mental health talked about, if at all?
- Do people bring these kinds of issues up? Do you as a service provider talk about them?
- For diabetic patients who might also have a mental health problem or substance use problem, how are multiple issues addressed?
- Do you think stress plays a role in how people manage their diabetes? How so?
- Are there any challenges in treating/preventing diabetes in your community, such as cultural or community barriers?
- Are there any culturally specific considerations that need to be taken into account when treating patients with diabetes?
- How thoroughly (if at all) do the different service systems in your community coordinate care?
- How thorough is follow-up care?
- What can service providers do to better serve those currently living with diabetes or prevent those at-risk of developing diabetes?

### Table A2

*Number of participants by focus groups*

<table>
<thead>
<tr>
<th></th>
<th>Bois Forte (n)</th>
<th>Lac Courte Oreilles (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individuals with T2D, group 1</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Individuals with T2D, group 2</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Social support persons, group 1</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Social support persons, group 2</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>Service providers, group 1</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Service providers, group 2</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Total</td>
<td>34</td>
<td>61</td>
</tr>
<tr>
<td>Research question</td>
<td>Guiding objectives</td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>1  How does social support impact the management of T2D in AI communities?</td>
<td>• What is the understanding of the role of social support in T2D in AI communities?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• How do the social contexts of Indigenous communities influence social support mechanisms?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• What are the mechanisms through which social support impacts components of T2D management?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• What roles are pertinent in these dimensions of social support; are these influenced by constructs such as gender and inter-generational factors?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• How can family, as a context of social support, be beneficial in T2D management?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• In which stages of T2D management is social support most optimal?</td>
<td></td>
</tr>
<tr>
<td>2  How can social support interventions address the underlying stressors that</td>
<td>• What barriers in T2D can social support help to overcome?</td>
<td></td>
</tr>
<tr>
<td>contribute to T2D inequities in AI communities?</td>
<td>• What are some considerations in implementing social support components in T2D management?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• What social support interventions can be incorporated into the community?</td>
<td></td>
</tr>
</tbody>
</table>
### Table A4

*Theme categories and sub-themes*

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perception of social support</td>
<td>• Importance of social support in T2D management</td>
</tr>
<tr>
<td></td>
<td>• Attitudes towards social support</td>
</tr>
<tr>
<td></td>
<td>• Uptake of social support</td>
</tr>
<tr>
<td></td>
<td>• Sources of social support provision – family, and community</td>
</tr>
<tr>
<td>Functions of social support</td>
<td>• Emotional support</td>
</tr>
<tr>
<td></td>
<td>• Instrumental support</td>
</tr>
<tr>
<td></td>
<td>• Positive reinforcement</td>
</tr>
<tr>
<td></td>
<td>• Enabling role</td>
</tr>
<tr>
<td></td>
<td>• Approaches in providing social support</td>
</tr>
<tr>
<td>Social and cultural contexts of social support</td>
<td>• Barriers to optimal T2D management – illness beliefs, especially denial, and the belief of not wanting to be a burden</td>
</tr>
<tr>
<td></td>
<td>• Strengths relating to the unique social and cultural contexts, namely 1) cultural identity, and 2) family, which has specific functions in social support such being a source of motivation, and care provision</td>
</tr>
<tr>
<td>Considerations in implementing social support components in T2D management</td>
<td>• Addressing stressors in T2D management</td>
</tr>
<tr>
<td></td>
<td>• Caregiver stress</td>
</tr>
<tr>
<td></td>
<td>• Balance</td>
</tr>
<tr>
<td></td>
<td>• Timing</td>
</tr>
<tr>
<td></td>
<td>• Challenges associated with the social and cultural aspects of Indigenous communities</td>
</tr>
</tbody>
</table>