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Family: The Bedrock of Support for American Indian Women Cancer Survivors

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Abstract

Cancer disparities among American Indian (AI) women are alarming, yet a dearth of research focuses on the role of family support for such women. The purpose of this research was to examine the composition of AI women cancer survivors' family support networks and the types of support that they provided. We used a qualitative descriptive methodology with 43 AI women cancer survivors and qualitative content analysis, which indicated that 38 participants (approximately 90%) reported that their families provided integral and varied forms of support, especially instrumental support throughout cancer experiences. Families were the bedrock of support for AI cancer survivors.

The leading cause of death for American Indian and Alaska Native women (AI/AN) is Cancer¹. Although it is difficult to get rigorous data on cancer among AI/AN individuals, AI/AN cancer death rates have not declined at the same rate as for White people². AI/AN women experience this disease at 1.5 times the rate of White women¹. Between 2001 and 2009, death rates for AI/AN men and women were actually amplified². Despite these disparities, little known research focuses on the family support networks of AI/AN women cancer survivors, creating a gap in knowledge in researchers and practitioners understanding on how to achieve greater health equity for these underserved and marginalized populations.

Because cancer rates and factors vary by gender, region, age, ethnic identity and culture, we examine AI women cancer survivors' family support systems separate from other minorities. For example, for AI/AN women, lung cancer rates continue to increase, despite lung cancer rates decreasing for AI/AN men³. Although AI/AN women and Whites had similar ovarian and uterine cancer death rates, these rates varied by tribes and regions⁴. Similarly, although breast cancer death rates are lower for AI/AN women than for Whites, for AI/AN women in

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particular regions of the country and age groups, rates of cancer deaths were actually higher⁶.

AI/AN women experienced higher incidence and death rates for colorectal and kidney cancers than AI/AN men experienced, and also higher incidence and death rates than that of White women⁷. In addition, although family support has been strongly associated with improved cancer outcomes throughout diagnosis, treatment and recovery, research on this topic among AI/AN individuals has been limited⁸. Thus, gender specific inquiries among AI individuals with cancer are needed to understand culturally relevant family support networks.

Family Support During Cancer

Social support is a key protective factor that improves the quality of life of those with cancer⁹. Studies conducted with women in the general U.S. population have even found that social support may protect women from the progression of breast cancer¹⁰. Family support also tends to be strongly desired by women with cancer¹¹. Extant research indicates that family support appears to be most important for cancer survivors immediately following their cancer diagnosis and during their first year following diagnosis, with the perceived helpfulness tapering off after this time¹¹. These studies were done among a mixed U.S. population, and although the cancer disparities experienced by AI women are alarming, research specifically on family support for AI women is virtually non-existent⁸.

In a review of the perceived needs of cancer survivors and their families, the need for more information from healthcare providers (preferably provided face-to-face) about cancer treatment and recovery was consistently reported as a concern¹². In addition, family members frequently reported that their concerns and questions were ignored by health care providers¹². This is especially concerning since increasingly medical care takes place in home settings, with family members frequently providing the majority of care¹³. Although family members are an important source of support for cancer patients, exploring how changes in the roles and increased burdens on family support systems impact both the patients and their families is warranted¹³.

Family Support During Cancer among AI individuals

The entire AI family is often involved in cancer treatment and recovery, and social support has been found to have a positive impact on coping with cancer¹². Yet, little research explores family support among AI women with cancer beyond its impact on initial cancer screening⁸. Bauer et al. (2005) examined the different forms of social networks reported by 40 AI cancer patients with 41 AI patients without cancer. They found that distinct forms of support came from separate sources, with companionship most often coming from friends, prayers coming from church support, and instrumental support coming from family⁸. No differences were identified across the forms of support provided by family, friends, church/community of AIs with and without cancer, and expressive social supports (e.g., companionship, emotional support, and advice) were reported as the most important by all⁸.

Instrumental support (e.g., financial, transportation, household maintenance) was ranked at the bottom of the list⁸.

Including the family in therapeutic programs has been found to be particularly important for AI individuals with cancer¹². Other literature has indicated that family can be both supportive for AI women with cancer, but that it can also potentially act as a barrier if caregiving responsibilities of children and grandchildren interfere with screening and treatment¹⁴. Given that family is central for AI/AN communities, the absence of research on the composition and role of AI women cancer survivor's familial support networks is both surprising and concerning. The purpose of this research was to explore AI women cancer survivors' familial support networks, examining both the composition and types of support provided by familial support networks.

Methods

Research Design

We employed a qualitative descriptive methodology to examine the familial support experiences of AI women cancer survivors. This is an inductive form of inquiry which is naturalistic, and also provides a deep and nuanced view of participant experiences that uses everyday language¹³. Qualitative description was used because it is especially appropriate for research projects with vulnerable and marginalized groups and because it is well-suited for understanding cultural nuances. This is, in part, because it focuses on the words and interpretations of participants, instead of placing the primary importance on the interpretation of the data on the part of the researcher¹³. The focus on the interpretation of findings by researchers is limited and focusing, instead, on the views and recommendations of the participants themselves makes this “a fine-tuned research design” that produces information that can then be used and applied to real world situations¹³.

Within the qualitative descriptive methodology, we used a community advisory board (CAB) comprised of health care professionals who work in the two metropolitan areas of Sioux Falls and Rapid City of South Dakota and leaders in the AI community. Although CAB members themselves did not conduct interviews, the CAB participated in all phases of the study. The responsibilities of the CAB were to: (1) identify community needs and concerns related to the research; (2) guide recruitment of participants and the dissemination of the results; (3) enhance community support and research involvement; (4) participate in data analysis; (5) participate in community-based and academic dissemination activities; and (6) participate in project evaluation activities. The CAB developed an interview tool consisting of demographic and qualitative questions designed to elicit new knowledge about participant experiences with cancer. The key focus of the investigators throughout the CAB process was to establish an atmosphere of trust and community partnership, as well as foster cultural humility through ongoing self-reflection. Our overarching research questions were: (1) “Who makes up AI women cancer survivors' familial social networks?” and (2) “What types of social support do they provide?”

Setting

This collaborative research was done in the state of South Dakota at: (a) the Avera Medical Group Gynecologic Oncology in Sioux Falls, an eastern community-based hospital in the Northern Plains region and (b) the John T. Vucurevich Cancer Care Institute, Rapid City Regional Hospital in Rapid City, a community-based hospital in the region. These hospitals were selected as sites because they are the main hospitals where AI women receive services in the Northern Plains region.

Sample

The participants in this study were 43 AI women cancer survivors ($n=14$ cervical cancer, $n=14$ breast cancer, and $n=15$ colon and other types of cancer survivors). We included diverse forms of cancer to assess the commonalities in forms of support and support systems that occurred across all cancer forms. Purposeful sampling was used to identify AI women cancer survivors who could answer the specific research questions of this study, and research ended after the data reached saturation and no new information was gained in the interviews (Sandelowski, 1995). The inclusion criteria to be in the study were: (a) in the last 10 years having had any form or type of cancer; (b) completing cancer treatment with no symptoms of the cancer returning; (c) being 18 years or older; (d) being female and self-identifying as an AI or AN; and (e) residing in South Dakota at the time of the interview. All participants must have completed cancer treatment before participating in the study.

Participant ages ranged from 32 to 77, ($M=56.33$ years, $SD=12.07$). For educational background, 97.7% of participants had at least a high school degree/GED. Almost half (49%) of participants indicated that their monthly household income was less than \$1,499. Many (32.5%) participants described their health as either *poor* or *fair*, and 67.5% reported their health as being *good* or *excellent*. The type of cancer participants had included: cervical ($n=14$, 32.6%); breast ($n=14$, 32.6%); colon ($n=5$, 11.6%); Non-Hodgkin Lymphoma ($n=2$, 4.7%); lung ($n=2$, 4.7%); and others forms of cancer ($n=6$, 13.9%). The majority of respondents ($n=39$, 90.7%) reported having a religious affiliation. Most participants (93%) had some form of medical insurance. The majority of participants ($n=36$, 83.7%) reported chronic illness, such as high blood pressure ($n=21$, 48.8%), diabetes ($n=16$, 37.2%), high cholesterol ($n=8$, 18.6%), arthritis ($n=13$, 30.2%), and asthma ($n=9$, 20.9%). Among older women aged 55 or older ($n=23$), 20 participants (87%) reported chronic health conditions: high blood pressure ($n=16$, 69.6%), diabetes ($n=10$, 43.5%), high cholesterol ($n=5$, 21.7%), arthritis ($n=8$, 34.8%), asthma ($n=5$, 21.7%), heart disease ($n=4$, 17.4%), and osteoporosis ($n=3$, 13%). The average amount of time participants had cancer was approximately 2.42 years ($SD= 2.19$) (see Table 1).

Data Collection

Before beginning data collection, Institutional Review Board approval from the following were obtained: (a) University of South Dakota, (b) Avera McKennan Hospital, (c) Rapid City Regional Health, and (d) Sanford Research Center. Participants signed a voluntary form of informed consent before beginning the interviews. A principal investigator (PI) and two research assistants who have extensive work experience with cancer survivors and AI individuals conducted the interviews. For recruitment, fliers were mailed to each of the

hospitals, announcements were made in the newspaper and on public radio, fliers were posted at different agencies and offices in the community, and finally, recruitment through word-of-mouth was done at additional sites in the community (e.g., churches or other local agencies). A total of 46 potential participants initially responded. Three respondents with a cancer history of more than 10 years were excluded from participating, making the final sample of 43. Interviews occurred at the locations the participants indicated they felt most comfortable, such as at participants' homes, or in private offices or conference rooms from June, 2014 to February, 2015.

Through collaboration with the CAB, a semi-structured qualitative interview guide was created. The interview guide was created following the community needs and priorities identified through the CAB and incorporated the research topics of the investigators. The CAB reviewed the guide and focused on making sure that the wording of each question was appropriate and made sense, in addition to checking for cultural appropriateness and relevance. To address our overarching research questions of "Who make up AI women cancers survivors' familial social networks throughout their cancer diagnosis, treatment and recovery?" and "What types of social support do they provide?," we asked participants questions, such as "Has your family been supportive?" and "What support did or do they provide?" The interviews were audio-recorded and were then transcribed word for word by graduate students. The interviews ranged from 30–120 minutes. Participants were compensated \$50 cash and were also given an additional gift card to cover any travel or additional participation expenses. The interview transcripts were entered into Nvivo (2015) data analysis software.

Data Analysis

Qualitative content analysis, which is often encouraged for qualitative descriptive studies^{13–15}, was used to encourage the emergence of themes inductively from participant interviews¹⁴. The process of qualitative content analysis included: (a) reading and listening to interviews several times for full immersion and to better understand findings in a holistic way; (b) coding of data section by section; (c) creating 430 preliminary codes, then these preliminary codes (or meaning units) were placed into larger categories with corresponding subcategories; (d) validating and analyzing these categories and subcategories, while exploring whether differences existed based on the types of cancer participants reported. The authors looked at key themes identified among each cancer subgroup and did not identify any differences based on cancer-types; thus, after finding no cancer-specific sub-themes related to the themes of this article, the themes that cut across category were focal for this analysis; (e) analyzing the content of the emergent categories with the use of in-depth analysis to synthesize codes into understandable themes, which included providing a definition for each of these; and (f) presenting these themes to participants and co-authors for member checking.

Authors attempted to contact all participants on at least three occasions so that they could participate in member checks. During member checks, participants were shown some of the key themes identified during data analysis along with some of the quotes that corresponded to each theme and asked if they felt those themes were representative of their experiences

and others in their community. Over half of the participants ($n=23$, 53.5%) engaged in member checks. Close to half ($n=21$, 46.5%) of the participants had phone numbers that were no longer functioning, and were, therefore, unreachable. Of those participants who were reachable, almost all engaged in member checks. Participants did not request any changes to the findings. There were no demographic differences between participants who engaged in member checks and those who did not. Throughout the data analysis process, co-authors de-briefed and discussed the salient themes that were being identified to ensure that what each author was finding was congruent with the other authors.

Strategies for Rigor

We followed the strategies for rigor outlined by Milne and Oberele (2005) specific to qualitative descriptive studies¹⁴. These included (a) *authenticity* to the goal of the research project; (b) the *credibility*, or trustworthiness of the findings; and (c) *criticality*, or deliberate decision-making procedures. Using a flexible and semi-structured interview guide encouraged participants to speak freely and in their own voice¹⁴. We also probed for more information to make sure participants' words were heard as they meant them to be, facilitating member checks, and using inductive analysis throughout to ensure that coding came from the data through conventional content analysis all aided us in following the strategies as outlined¹⁴. Authenticity was also promoted by probing for potential bias throughout and all study authors engaged in multiple rounds of de-briefing and peer review¹⁴.

Results: Family Support through Cancer Experiences

Cancer survivors gained support from a number of sources throughout their cancer diagnosis, treatment and recovery. In the following sections, the specific family members that provided support are identified, and the types of support they provided are presented. Intergenerational support was reported by most participants, and although participants reported receiving support from a variety of sources, grandchildren were the most prominent sources of support reported. In response to the interview questions, a total of 38 participants (approximately 90%) indicated their families had provided support throughout their cancer experiences. Over half ($n=22$, 52%) indicated that their family had 'helped out,' or provided instrumental support through their cancer experience. In the following sections, participants were given anonymous numerical identifiers to demonstrate how quotes arose while also retaining participant confidentiality.

Support Across Various Family Members

Participants received support from a broad range of family members. When asked about their support system, Participant 8 replied, "My people who take part in our ceremony. We'll call to Tiyospaye. Tiyospaye means family, it don't [*sic*] just mean you're blood relatives, it means the people that you pray with and come together with." She described the support she received from these individuals: "They talk to you. They call you. They pray with you. They check on you. They just do everything. They're just real supportive. They call and check on you. They come visit you. They bring you food." Participant 31 indicated her supports as being, "My mother, friends, family, brother, sisters, and my kids." Participant

19's family lived far away, but she stated, "Oh yes, my original family [family of origin] has been so supportive. You know, they were, like you know, they called me every day." Similarly, Participant 41 indicated all of her family (e.g., parents, kids, partner) had been supportive.

When asked what types of support they provided, Participant 41 stated "They do everything for me if I want." She went on to add, "If I feel like eating something, they get it for me, or if I feel like cooking that day, they'll go and buy me the stuff to cook." Participant 15 similarly described her support system, "My children have [been supportive] and my aunt, my mom's sister is really supportive, and my partner he's really supportive." Finally, Participant 12 described her family support, which included, "My sisters, and my brothers, and my boys, I got just two boys, and my grandkids, I got granddaughters in their 20s." When asked what they do, Participant 12 explained:

Oh you know, they stand by me, and, and they help me, if I need help, they help me, you know...and stuff like that. And my boys really help me too, so I'm okay. You know? They help me quite a bit, my family come, they cook, and they help do this and that, you know, and they stay, my sisters, both of my sisters stayed for about two weeks with me.

Family support included support from a variety of intimate and extended family members, including both emotional and instrumental forms of support. The focus now turns to participants' descriptions of the specific forms of support they received from each of these types of family members.

Extended Family Support

Participant 7 described how her family and particularly her extended family supported her, indicating that this was characteristic of the family support that was normative in her tribe, as she described:

My family rallied. We had a warrior of supporters, you know, making sure I was at my appointments, and having the right...I guess having the right words. Maybe that they said to me during that time in my life ... positivity ...they took care of my children when I needed them, too. Umm, it just became a larger family than what I have just on a normal, regular day. You know, the family really came to my rescue ... they were really strong supporters, and to me, that is a really strong Lakota... you have extended family, you have extended cousins, you have extended aunts, you know? So I think I felt that a lot.

Participant 8 also described her extended family support, who included, "...some cousins that we were raised together with my grandma." She explained, "They come and help me clean up around the yard, or you know? Do little odds and ends for me. Clean my basement, or just anything. They'll come over." Participant 3 went on to add, "I have a brother-in-law who's very helpful. If I need anything done like bathroom fixed or my sons they mow my lawn. My sister cooks but I always like to try to do my own cooking in my house." Finally, participant 37 described her various support systems:

My sister would come up and ask me how I was doing, and my nephew, and my son was there. Every time I had to go to the doctors [family] would walk me to the car and then walk me back in the house and up and down then to check on me.

The support AI women cancer survivors received from extended family predominately included instrumental support, such as assistance with childcare, cooking and transportation. Of note is that this support often came from family members outside the nuclear family, with participants reporting support from more distant relatives and family members.

Children Support

Adult children were also a core support system. When asked whether her family had been supportive during her cancer treatment, Participant 33 indicated, “Yes. I mean they help me around the house and stuff.” However, important to this participant was that she also had boundaries with her children when it came to emotional support, and used formal health practitioners for this, stating:

Like my oldest one she’s like 22. She’ll cook or clean. Just normal everyday things. But like support if I needed someone to talk to. I couldn’t do that to my kids because they still don’t understand, and I don’t want to scare them or anything. But I have a counselor who calls me every Friday so if anything I’ll talk with him.

Participant 4 described her family support coming from, “Just my daughter and my grandchildren.” When asked about the types of support they provided, she indicated, “Oh they come around me and they bring me food or bring me gifts, you know, and although when I was going through treatment, I couldn’t eat because they had to put a catheter in my stomach.” Likewise, Participant 28 added: “My daughters also would come and cook a meal for me or just make me some tea and sit there and visit with me.” Participant 8 also described:

They’re always there for me to...my kids are always there for me. They’ll help me do anything, you know? They bring me to my appointments... and my sons drive me here and there, you know? They help. They come and help me clean up, they’ll come cook for me. I don’t need ‘em to, but they’ll come and...just to be with me and they’re always around me.

Finally, Participant 3 explained,

My family has really been supportive. I have 2 boys and 1 girl and I have 5 sisters and 3 brothers, 4 brothers actually. I have 2 half-brothers and 2 real brothers. And they’re very supportive. My children are very supportive. You know they worry about me. I don’t know they’re always there for me. I have, my oldest boy, he’s like a, I don’t know, he’s kind of overbearing sometimes. I always have to tell him I’m alright. He’s always calling, texting, and he even got me a cell phone so that way I can keep track of you. So I do, I have a really good family support. I have friends that are always calling or always checking on me. They stop and see me. They know where I work and so I have a very good family support. My aunties. I know they’re always there for me.

These results indicated a strong ethic of caring for parents who were in need, as evidenced by adult children's demonstrable commitment and care to their parents. Participants reported receiving both emotional and instrumental support from their children, although for some participants, making sure their children were protected from the emotional burden of cancer was important.

Grandchildren Support

Notably, about 20% of participants ($n=8$) emphasized how their grandchildren helped them cope with and provided support with their cancer experiences. When asked what helped her cope with cancer, Participant 14 described how her close relationship with her granddaughter gave her strength, "She's the one who keeps me strong." When asked how she helped, she added:

Just her being here. It's what she says and does to you. So I think she helps me a lot coping with anything. It's like she *knows*. If I'm real sad, she'll come up to me and say, "Don't be sad." I don't know how she knows, but she's helped me a lot.

Participant 14 also emphasized her granddaughter's support when describing her general family support, describing support from: "...my youngest daughter, my husband, and my granddaughter, my youngest granddaughter. She lives in Rapid City. She says, 'Grandma, you're sick but we're gonna fight it!'" Participant 12 also described receiving support from her granddaughter:

So she keeps me going ... and that's good, you know? Cause we do a lot of things. We go to the park, she rides her bike, you know, we play cards, or you know, something, you do not pity yourself. You do what you have to do, and that's a good thing.

Similarly, Participant 10 described her granddaughter's help:

My little granddaughter helps me make the bed and she gets me my warm water because I can't drink cold water when I'm on chemo. It freezes everything up and she knows it so she makes warm water and gives it to me.

Participant 6 described:

Yeah, my granddaughter, one of my granddaughters came and stayed with me until I was able to get up on my own and then I moved in at my daughter's house. She was living in Gordon, so I moved in with her because her hallways and bathroom were more accessible with my wheelchair and stuff, so I moved in with her until I was completely healed and got off my boot and stuff and was able to walk on my own.

Her husband's family was also supportive, as she explained, "Well, they come to visit, they encourage me. I mean, I really couldn't ask for anything better." She added,

He helped, and showering, and those kids that I helped put through school, those are the grandkids that come and help. They come and help, you know, like, helping clean house, and when I needed help, and coming and fixing meals and so, you know.

Thus, grandchildren not only provided instrumental support, but they also tended to provide survivors with the meaning and motivation to cope with and continue on their journey to recovery.

Sibling Support

Siblings, and sisters in particular, provided important support to AI survivors. Participant 28 reported the importance of her family support system, particularly regarding the support from her sister:

Yes, my family has been supportive. My sister would drive all the way from [location], to come with me, and my husband came with me, ... when I had surgery for my mastectomy, my sisters were there and my husband was there.

Participant 23 indicated her sister, “She comes up and checks on me.” Another sister’s support was described:

She must be about 69 years old. Anyway, she comes up and checks on me and she’ll put my groceries away, or, you know, she’ll clean up in my kitchen or dining room area if there’s any dishes but I never leave dishes myself. My kids are bad for leaving their dishes wherever they sit. So anyway, she’ll come clean up that mess and she’ll haul my garbage out to the garbage can, I have a large blue garbage can out in my yard and it’s really hard for me to get there and lift that bag up, you know.

Sibling support was important for participants and predominately included support from sisters. These results indicate that the importance of sisters continued past childhood and was extended to the care and commitment of sisters for each other into adulthood.

Partner/Husband Support

Partners were also frequently described as being an important form of support. Participant 28 described the support she received from her husband:

I feel like my family has been supportive, especially my husband. ... When I had my mastectomy, I wasn’t able to lift my hands above my head or dress myself or bathe myself, and my husband bathed me and took care of me.

Participant 15 described how her partner helped her when she wasn’t feeling good:

If I’m tired, he’ll tell me “let’s go for a walk,” and we’ll go for a walk. Or he’ll tell me to lay down and take a nap, but I’m not the type of person to lay down and take a nap.

Participant 16 mentioned:

My husband was with me the whole time. As soon as we were done with the chemo, he’d take me out to dinner. I would just.... Never got sick. And like my mother, my sisters, and my brother and sisters in Christ would send cards or call me.

Partners were important for survivors because they provided both emotional and instrumental support. These findings indicate that participants received support from extended family, children, grandchildren, siblings, and partners, and that the types of support received included both emotional and instrumental support.

Discussion

Families were the bedrock of support for AI women cancer survivors, as one participant mentioned how her family, including extended family, “rallied” and how she had a “warrior or supporters.” Although immediate family support was important, these results highlight the particular importance and prominence of intergenerational support. Family support for these participants came from children, grandchildren, siblings, cousins, aunts, and parents, and could include informally adopted family members. The types of support provided by extended family, children, grandchildren, siblings, and partners did not significantly differ across cancer subgroups. All groups provided instrumental (e.g., housework, cooking, yardwork, transportation, physical care) as well as emotional (e.g., spending time with the participant, checking on the participant, providing motivation, recreating with the participant) support.

The particular meaning and importance attributed to each form or type of support may differ depending on the source of the support. For example, grandchildren seemed to hold a special place in many women’s lives, providing them emotional support and motivation, whereas partners engaged in more intimate care, such as providing bathing assistance and going on walks or to dinner with women. The prominence of the role of grandchildren in the lives of grandparents is consistent with census data suggesting that over half of AI grandmothers care for grandchildren for a period of at least five years^{16,17}. The support women in our sample received from their grandchildren is in contrast to other literature on the barriers faced by older minority women with cancer where obligations for caring for grandchildren has sometimes been a barrier to cancer screening and treatment¹⁷. Although differences across the different types of family support was not focal to this inquiry, it warrants future investigation.

Consistent with Bauer et al.’s (2005) research, instrumental support tended to be part of the types of support family provided, and this was present across the extended family, children, grandchildren, and partner categories. Indeed, family helped with cooking, childcare, cleaning, lawn care, transportation and doing other household chores. This assistance was integral, particularly because cancer survivors may have physical limitations, particularly after surgery. Cooking and food related activities were spoken of frequently, which is consistent with AIs sharing food in family settings (Author(s), In Press).

Not only did family provide instrumental support, partners and families provided companionships and emotional support. One participant spoke about going for walks, and exercising with her partner, which not only provided companionship, but aided in physical health. Children would “sit with” and “have conversations with survivors,” but participants were mindful about not over-burdening children with cancer specific experiences, choosing to speak to health practitioners about such challenges. Survivors emphasized the importance

of family members “checking in” and showing they cared. Families, and grandchildren in particular, provided emotional support and motivation for women as they went through these challenging experiences. They offered encouragement and joy in times where these factors are indispensable.

Limitations and Future Research

Given the current lack of research, more studies examining family support are needed. This qualitative study is not generalizable beyond its setting. Though we did not find differences across participants with differing types of cancer, future studies can replicate or extend this work with larger samples or quantitative studies. Results are self-report only, and direct observation of family support systems may provide important insights. Differences also need to be examined across the specific contexts of the 573 federally recognized tribes⁵. It is possible that the type of support, or the form of family support provided may differ between tribes. The scope of the inquiry and all questions on the interview guide were all directed toward their cancer experiences. These directed questions made it likely that participants spoke of salient cancer-related family support; however, some of these family support themes may be present beyond cancer experiences. We also did not specifically compare urban versus rural cancer survivors. Future research could also explore this area as it relates to family support, since research indicates that those living in rural areas may benefit especially from support from social media programs to provide education about cancer screening and treatment for patients and their family members²⁴.

Implications for Practice

Together, the instrumental and emotional support of families were profoundly integral, not only for AI women survivors’ daily care, but also their emotional health, household activities and maintenance, and physical exercise. By the participants’ accounts, families met the majority of AI women survivors’ cancer-related needs; without their support, these needs would likely go unmet or be met through costly formal healthcare practitioners. Families can be instrumental protective factors for women going through hard times (Author(s), In Press). However, as noted by one participant, a desire to not over-burden family members suggests that there may be a need for support from non-family sources and institutional support. In addition, given that almost half of participants had monthly incomes of less than \$1,500, families may play an even greater role in resource deprived settings. For example, one way this was demonstrated is in the importance of family members providing transportation for participants who did not otherwise have a way to get to their appointments. However, additional financial support may be needed to take some of the pressure of care off already over-burdened populations.

The far-reaching implications for practice with AI cancer survivors are evident. First, other research has found that social support was one of the most important factors regarding AI constructive coping, particularly regarding contributing to survivors’ having a “fighting spirit” or personal resilience in dealing with cancer¹⁸. Likewise, families can serve as important motivators for receiving screenings and treatments, as was the case for women in Becker, Affonso, and Blue Horse Beard’s (2006) study that used talking circles to understand AI women’s cultural meanings of cancer in the Northern Plains region²⁵.

Other programs have included family members in art therapy interventions with AI cancer patients that included the family or in story-telling about their cancer experiences^{12,19}. It should be noted that extended family and adopted family members are normative and limiting the definition of “family” to nuclear or even biological members may be inappropriate and harmful²⁰. Medical facilities should provide culturally sensitive care by being inclusive of the definitions of family that patients determine. This is congruent with research demonstrating that cancer programs that are culturally inclusive are more effective²¹. Because of the long history of medical exploitation and inadequate health and social programs, the need for culturally sensitive care is essential²².

In addition, these findings indicate that although family members provide much of the needed resources for cancer survivors, there is an opportunity and need for nurses and healthcare practitioners to provide emotional support. This is a particularly important point since many women indicated not wanting to “burden” their family with their emotional challenges related to cancer in addition to education for family and community members about cancer²³. Family members may also benefit from additional information and support provided through social media programs²⁴. Congruent with the findings from Bauer et al. (2005), results from this research indicate that family is the principle source of support for cancer survivors. Thus, prevention and intervention efforts should incorporate, build upon, enhance, and nurture the important roles that family members play in AI women cancer survivors’ experiences⁸. A central message of this research is that family support and involving family throughout the cancer screening, treatment, and recovery process is essential to maximize the effectiveness of interventions for cancer in AI/AN women.

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Table 1Demographic Characteristics of the Sample ($N = 43$)

Variable		N or Average	%
Age, $M(SD)$	Range: 32 to 77 (years)	56.33	(12.07)
Education, n (%)	Lower than high school diploma/GED	1	(2.3)
	High school diploma/GED	15	(34.9)
	Greater than high school diploma/GED	27	(62.8)
Marital status, n (%)	Married	12	(27.9)
	Divorced	18	(41.9)
	Separated, Widowed, Single	11	(25.5)
	Other	2	(4.7)
Perceived health, n (%)	Poor or fair	14	(32.5)
	Good or excellent	29	(67.5)
Monthly household income, n (%)	Less than \$1,499	21	(48.8)
	\$1,500-\$2,999	14	(32.6)
	More than \$3,000	8	(18.6)
Type of cancer, n (%)	Breast	14	(32.6)
	Cervical	14	(32.6)
	Colon	5	(11.6)
	Lung	2	(4.7)
	Non-Hodgkin Lymphoma	2	(4.7)
	Others	6	(13.9)
Religion	Yes	394	(90.7)
	No	4	(9.3)
Health insurance	Yes	40	(93.0)
	No	3	(7.0)
Time with cancer	Ranged from 3 month to 9 years	2.42	(2.19)