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Understanding the social and community support networks of American Indian women cancer survivors

Catherine E. Burnette ^a, Jessica Liddell^a, Soonhee Roh^b, Yeon-Shim Lee^c and Hee Yun Lee^d

^aSchool of Social Work, Tulane University, New Orleans, LA, USA; ^bDepartment of Social Work, University of South Dakota, Vermillion, SD, USA; ^cSchool of Social Work, San Francisco State University, San Francisco, CA, USA; ^dAcademic Chair on Social Work and Health, School of Social Work, The University of Alabama, Tuscaloosa, AL, USA

ABSTRACT

Objective: Cancer is the leading cause of death among American Indian and Alaska Native (AI/AN) women, and although cancer disparities among AI women are alarming, there is little research focused on the topic of social support and cancer treatment and outcomes.

Design: A community advisory board was used to develop and administer the project, and a qualitative descriptive study methodology was used. This research was conducted in partnership with two community-based hospitals in the Northern Plains. The sample included 43 AI female cancer survivors who were interviewed with a semi-structured interview guide. The data were analyzed using content analysis.

Results: Emergent themes revealed that AI cancer survivors' non-familial support systems included friends ($n=12$), support groups ($n=6$), churches ($n=10$), co-workers ($n=5$), communities ($n=4$), support from health practitioners ($n=3$) and additional forms of support.

Conclusion: Results indicate that survivors' networks are diverse, and support broad prevention programs that reach out to churches, community groups, and online forums. These sources of supports can be enhanced through sustainable community-based infrastructures.

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Cancer is the leading cause of death among American Indian and Alaska Native (AI/AN) women, who experience it at 1.6 times the rate of Caucasians (Espey et al. 2014). Although historically the data on AI/AN cancer has been scarce, the most reliable data has included death records and cancer incidence records from state cancer registries, which have been linked with Indian Health Service registration data to identify AI/AN people correctly (Centers for Disease Control (CDC) 2016). Overall, these data indicate that cancer death rates for white people declined more quickly than for AI/AN people; between the years of 2001 and 2009, death rates actually increased for AI/AN men and women (CDC 2016).

CONTACT Catherine E. Burnette  cburnet3@tulane.edu  School of Social Work, Tulane University, 127 Elk Place, #8906, New Orleans, LA 70112, USA

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The rates of cancer incidence, along with death rates often vary by cancer type, region, and sex. For example, although lung cancer has decreased among AI/AN men since 1997, it continues to increase for AI/AN women (Plescia et al. 2014). For ovarian and uterine cancer, AI/AN women and Caucasians have similar cancer death rates, yet these rates vary substantially by geographic region (Singh et al. 2014). Although the rates of breast cancer deaths tend to be lower for AI/AN women overall, it is concerning that they have not seen the same decline in death rates that white women have experienced (White et al. 2014). For colorectal cancer, incidence rates are higher overall for AI/ANs, and AI/AN women experience higher death and incidence rates than both their male counterparts and Caucasian women (Perdue et al. 2014). Finally, kidney cancer incidence and death rates for AI/ANs are nearly twice that of Caucasians, with AI/AN women experiencing significantly higher rates than both AI/AN men and white women (Li et al. 2014). Although cancer disparities among AI women (to whom the scope of this article is limited) are alarming, there is a dearth of research focused on the topic, particularly on the social and community support networks among these women (Bauer et al. 2005).

Social support

Social support is an important factor influencing the quality of life among cancer survivors (Luszczynska et al. 2013). Social support has been found to be particularly protective against the progression of breast cancer among women in the general U.S. population (Nausheen et al. 2009). Although social support has been found to be associated with positive AI coping with cancer (Zucca et al. 2010), *only one* article was found that explicitly focused on social support among AI women with cancer (Bauer et al. 2005). AI/ANs belong to 567 federally recognized tribes (Bureau of Indian Affairs 2018), along with state recognized tribes and tribes outside either jurisdiction, with a trust responsibility that requires the U.S. Federal government to provide for their healthcare (U. S. Commission on Civil Rights 2004). Given the significant disparities at present, the goals of this trust responsibility have not been met (U. S. Commission on Civil Rights 2004).

Because cancer rates and associated factors tend to vary by gender, geographic region, and age, ethnic identity and culture may also play an important role in impacting the social support experiences of AI women's cancer survivors. AI women utilize support from their social networks to cope with a range of health problems, including cancer (Canales 2004; Guadagnolo et al. 2009). Social supports may be especially important for AI women cancer survivors' because they are better suited to addressing some of the social and psychological effects of cancer that extend beyond the physical impact of cancer (Sammarco and Konecny 2008; Sapp et al. 2003; Wyatt and Friedman 1996). Cancer survivors living in rural areas may be particularly vulnerable because they are at increased risk for social isolation, because of the long distances frequently required to travel to access services, and the limited ability for them to receive continual monitoring of their physical and mental wellbeing (Doorenbos et al. 2011; Wilson, Andersen, and Meischke 2000). Previous research has also suggested that rural cancer survivors may especially need additional emotional support following cancer diagnosis because of the increased infrastructure barriers they face (Wilson, Andersen, and Meischke 2000).

Support in AI communities is often characterized by a mixture of both formal and informal resources and tribally-based assistance, and the forms this takes can vary substantially by tribe (Beals et al. 2005; Buchwald, Beals, and Manson 2000). Because of the long history of inadequate health and social services, informal forms of support, such as that provided by the community or friends, may be especially salient for AI cancer survivors (Canales 2004; Canales et al. 2011; Garrett, Baldrige, Benson, Crowder, and Aldrich 2015). Furthermore, some patients may avoid, or have ambivalent feelings about receiving support from formal institutions such as hospitals or social service agencies, because of this history of oppression, making an analysis of the role of informal social supports especially relevant (Broome and Broome 2007; Burnette 2018; Burnette and Figley 2017; Canales 2004; Canales et al. 2011; Garrett et al. 2015).

Bauer et al.'s (2005) article examined the social network topology of 40 AI cancer patients with 41 non-AI controls. Despite no differences being identified across the topologies of AIs and non-AIs, expressive social supports (e.g. companionship, emotional support, and advice) were reported as the most important by all (Bauer et al. 2005). Instrumental support (e.g. financial, favors, household maintenance) was not ranked as important (Bauer et al. 2005). Bauer et al. (2005) reported that these forms of support came from distinct sources, with companionship most often coming from friends, prayers coming from church support, and instrumental support coming from family (Bauer et al. 2005). Given the striking absence of research on AI women cancer survivor's social support, the purpose of this research was to explore their non-familial social and community support networks.

Methods

Research design

This research was informed by the creation of a community advisory board (CAB), which consisted of AI leaders in the community, health care practitioners from the AI community, and social workers from community social service agencies. The CAB's mutually agreed upon primary tasks were to: (1) identify project-related community resources and topics of concern; (2) provide guidance on how to recruit participants, along with dissemination of results; and (3) promote community support and community engagement for this research. This qualitative descriptive methodology explored the experiences of AI women cancer survivors relating to non-familial social support. The over-arching research questions were: 'Who do American Indian women cancers survivors go to for social and community support?' And 'What types of support do they receive?'

Qualitative description is a naturalistic inquiry where themes emerge inductively from data with a goal of a rich account of experience that is presented in easily accessible language (Sullivan-Bolyai, Bova, and Harper 2005). This can be germane to working with ethnic minority populations and for understanding cultural distinctions, because it describes a phenomenon with participants' own words rather than through the more theoretical interpretation of researchers (Sullivan-Bolyai, Bova, and Harper 2005). Sandelowski (1996) and Sullivan-Bolyai, Bova, and Harper (2005) have stated that this method enhances the internal validity of studies because it seeks to answer questions in participants' own words, and decreases competing explanations.

Setting and sample

This research was conducted in partnership with two distinct community-based hospitals in the Northern Plains: (a) the Avera Medical Group Gynecologic Oncology in Sioux Falls, Eastern South Dakota; and (b) the John T. Vucurevich Cancer Care Institute, Rapid City Regional Hospital in Rapid City, Western South Dakota. These sites were chosen because they are the primary community/regional hospitals serving AI women in the Eastern and Western parts of South Dakota, respectively.

The sample includes 43 AI female cancer survivors ($n = 14$ breast cancer, $n = 14$ cervical cancer, and $n = 15$ colon and other types of cancer survivors). The topic of social support was explored across cancer types to assess the underlying themes of cancer survivors' social support systems, rather than looking for differences based on cancer type (although the potential for differences across cancer type was assessed in the data analysis process). Purposeful sampling was used to identify which individuals would be best able to answer questions about female AI experiences with cancer (inclusion criteria included all AI women over the age of 18 living in the area who had cancer within the past 10 years but who did not currently have cancer at the time of the interview). New participants stopped being recruited after the data reached saturation (when no new meaningful information was attained in interviews) (Sandelowski 1995). Inclusion criteria for participants included: (a) a history of any type of cancer within the previous 10 years; (b) completion of cancer treatment without recurrence at time of interview; (c) identifying as female; (d) being aged 18 years or older; and (e) residing in South Dakota.

Table 1 presents a summary of selected demographic characteristics. Among participants, ages ranged from 32 to 77, with a mean of 56.33 years ($SD = 12.07$). For education, 97.7% ($n = 42$) of participants had at least a high school degree/GED. Approximately 49%

Table 1. Demographic characteristics of the sample ($N = 43$).

Variable		<i>N</i> or Average	%
Age, <i>M</i> (<i>SD</i>)	Range: 32–77 (years)	56.33	(12.07)
Education, <i>n</i> (%)	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, <i>n</i> (%)	Married	12	(27.9)
	Divorced	18	(41.9)
	Separated, Widowed, Single	11	(25.5)
	Other	2	(4.7)
Perceived health, <i>n</i> (%)	Poor or fair	14	(32.5)
	Good or excellent	29	(67.5)
Monthly household income, <i>n</i> (%)	Less than \$1499	21	(48.8)
	\$1500–\$2999	14	(32.6)
	More than \$3000	8	(18.6)
Type of cancer, <i>n</i> (%)	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	39	(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)

($n = 21$) of participants' monthly household income was less than \$1499. While 32.5% ($n = 14$) of the sample self-reported their health as poor or fair, 67.5% reported good or excellent health ($n = 29$). The cancer-type of participants included: breast ($n = 14$, 32.6%); cervical ($n = 14$, 32.6%); colon ($n = 5$, 11.6%); lung ($n = 2$, 4.7%); Non-Hodgkin Lymphoma ($n = 2$, 4.7%); and others ($n = 6$, 13.9%). The majority of respondents ($n = 39$, 90.7%) described engaging in religious practices, and 93% ($n = 40$) of participants had medical insurance. Finally, amount of time with cancer was, on average, 2.42 years ($SD = 2.19$).

Data collection

Prior to the recruitment of participants, approval from the Institutional Review Board was obtained from four institutions: (a) University of South Dakota, (b) Avera McKennan Hospital, (c) Rapid City Regional Health, and (d) Sanford Research center. Before being interviewed, participants received information and informed consent and signed a consent form. Authors of this paper and two trained research who had extensive experience with AI samples, conducted the interviews.

Participant recruitment included mailing fliers to cancer survivors at the focal hospitals, posting fliers, running newspaper and public radio announcements, along with word-of-mouth recruitment at community agencies and/or churches. Among the 46 who responded, the three respondents with over 10 years of cancer experience were excluded, resulting in the final sample of 43 participants. Interviews took place at participants' preferred locations (i.e. participants' personal residence, a private room at the hospital, a private conference room at community church, and the author's office) between June 2014 and February 2015.

The semi-structured interview guide was created collaboratively through series of meetings with the CAB. Qualitative questions were developed through focusing on the topics of research together with community priorities and needs expressed by the CAB. The CAB assessed the guide for cultural appropriateness and ensuring the relevance and readability of questions to AI women cancer survivors. Examples of interview questions included, 'Do you have support systems outside of your family? What types of support have you received from them?' The audio-recorded interviews ranged from 30 min to 2 h in length, and participants were paid \$50 cash for their participation. An additional gift card was provided to cover travel and participation expenses. Three master of social work students transcribed the interviews, which were entered into NVivo (2015) data analysis software.

Data analysis

Data analysis followed qualitative content analysis, the analysis suggested for qualitative descriptive methodologies (Milne and Oberele 2005; Sandelowski 2000; Sullivan-Bolyai, Bova, and Harper 2005), and which allows codes to emerge from the data (Milne and Oberele 2005). First, immersion was achieved by author(s) reading and listening to interview transcriptions multiple times to gain a sense of the whole. Second, exact words were highlighted and notes were made to capture key concepts. Third, 430 initial codes, or *meaning units* were derived (Graneheim and Lundman 2004). Fourth, initial codes were organized into overarching categories with subcategories under each. Co-authors

checked and validated these categories and subcategories and examined whether any recurrent patterns of variation were present across cancer types. After no such differences were found, categories were organized into meaningful clusters, and a definition was created for each cluster (Patton 2002). Sixth, emergent clusters with their respective quotes were presented to participants for member checking (i.e. ensuring interviews and interpretations of data were correct, according to participants' perspectives). All participants were invited to engage in member checks, with over half ($n = 23$, 53.5%) participating in this process. Research team members reached out on three occasions for member checks, although close to half of participants ($n = 21$, 46.5%) had disconnected phones and could not be reached.

Strategies for rigor

Using Milne and Oberle's (2005) guidelines to enhance rigor in qualitative descriptive studies, (a) *Authenticity* (i.e. remaining true to the aim of the research); (b) *credibility* (i.e. the trustworthiness of findings); (c) *criticality* (i.e. strategic decision-making throughout the research process) was ensured in the following ways: (a) using a semi-structured interview guide, to encourage participants to speak freely; (b) ensuring participants' voices were prioritized by inquiring as to the depth and clarity of participants' meaning; (c) ensuring that participants' intended meaning were precisely represented by conducting member checks; and (d) ensuring that coding was inductively derived from the data through the choice of conventional content analysis, an inductive analysis method. In addition to the strategies already listed, authenticity was promoted by reflecting on potential bias and engaged in peer review to ensure study integrity (Milne and Oberle 2005).

Results

AI survivors' support systems included friends, church, cancer survivor and related support groups, community and neighborhood support, and support from health practitioners. It should be noted that although 64% ($n = 27$) of participants described some form of support system(s) outside of the family, 69% ($n = 29$) of participants also described the need for additional social support. The forms of social support outside family included friends ($n = 12$), which encompassed friends who were both cancer survivors and those who hadn't experienced cancer, and from in person and online support groups ($n = 6$), support from church ($n = 10$), from co-workers ($n = 5$), community support ($n = 4$), and support from health practitioners ($n = 3$). In the following themes, participants were given anonymous numbers to demonstrate that quotes arose across a variety of women while also maintaining participant anonymity.

Friend support

AI cancer survivors found friends through personal connections, support groups, and online social media. These friends provided both emotional and instrumental support to AI cancer survivors. Some women reported this support from friends entailing friends checking in on them and praying for them. When asked about her support system, Participant 21 mentioned, 'I had a lot of friends that would call and say they

were praying for you. You know, that was really big'. Participant 20 talked about her friend and survivor support system, 'I have good friends that check on me. Some are on Facebook and some are just private friends that check on me'. She added, 'There is a support group here'. Participant 27 went to a cancer survivor support group, because she said, 'I felt, you know, welcomed'. Participant 24 stated, 'I have a few friends that are cancer survivors. And then I'm on an online support group'.

Women found support through both in-person friends, as well as connections on social media. Participant 18 also stated:

I had friends that were very supportive, and I also had the support of other females who had breast cancer who I could talk to, and I also went online ... where they had chat rooms where they could talk with other survivors.

Some women received additional emotional support through non-cancer related support groups like Alcoholics Anonymous (AA). Participant 13 stated, 'Yes, I have close friends. People that are in the church, and people that are in Alcoholics Anonymous', who offered, 'listening, a shoulder to lean on, prayers'. Participant 4 also mentioned, 'I have the AA group and friends that I have. You know I have several good friends that I can lean on times of need'. Women received support from friends who came from a diverse range of sources, including friends who provided emotional and instrumental support specifically related to their cancer, and friends who provided general support. Women also received support from both friends that were both physically present, and from friends on online sources.

Church support

Church support was another source of support for AI women with cancer. Women conceptualized this support as both coming from individuals at the church and as coming from the church community as a whole. Similar to the form of support offered by friends, church support took the form of both emotional and instrumental support. Participant 28 described:

I have a lot of Christian woman who are friends. ... and they would just call me and see how I was doing and they would stop by if they were in the area and they would just come and let me know that they were thinking about me and they were praying for me.

Providing an example of the simultaneous emotional and instrumental support offered through the church, Participant 28 appreciated, 'Their encouragement and their visits and they would send gifts'.

Church support also appeared to be unique because of its regularity and dependability for participants. Participant 22 described the importance of her consistent church support, 'I call every once in a while, for prayer. We see each other about once a week'. In describing the type of support Participant 22 received from her church network, she added: 'I had an offer to give me a ride if I needed it, from one lady, she said she'd give me a ride to the doctor if I needed it'. Participant 17 described her church community, stating:

Those people are really nice. They brought us cooked meals for a week and they checked on us, called, see how I was feeling. The pastor prayed for us and everything. You know, they were a good support there too.

Finally, participant 35 described, 'I'm a Catholic. And I, it's real supportive. We all take care of each other. We're all there for each other when something happens'. Religious support was also not limited to Christian practices and churches, with participants also noting support from other spiritual figures. Participant 34 noted about her spiritual leader: 'She really encourages the sweet grass and the smudging. She really does encourage that. She really is a wonderful woman. We're really blessed to have her'. Church support took a variety of forms for participants, and was especially important not only because of the practical and emotional resources it provided, but also because of its connection to participants own faith and beliefs.

Co-worker support

Several women mentioned the importance of co-worker support. As with other forms of support, participants described their co-workers as offering a mixture of types of support. As Participant 16 described:

They were beautiful at my workplace. ... My boss said, she owned the place, she said if I felt sleepy I could go sleep on my car or lay on the couch or go home, and they would pick up the slack from my treatments.

Participant 5 also described co-worker support, 'Like some of them would come over with me and visit with me and say, "Oh ____, you're back!" ... and they come in, and I give them coffee or tea, and we visit'. Co-worker support was important for providing individuals with emotional and instrumental support in their professional lives, distinguishing it from the support they received from other sources.

Community and neighborhood support

Community and neighborhood resources was an additional source of social support for participants. Regarding the AI community, close to half (43%, $n = 18$) indicated that they didn't feel support, whereas about 21% ($n = 9$) indicated they did feel support, from both the AI community and the general community (total 43%, $n = 18$). For some participants, the importance of this source of support is that it provides a distraction from cancer itself. Participant 12 spoke about her neighborhood friends' support being comprised of companionship and fun, describing: 'Well they come over and visit and talk. We talk about different things, a long time ago, things that happened a long time ago, and we laugh, you know ... They bring a movie over, and we watch movies'. Alternatively, some participants described this support as being important because of the connection they felt over sharing a personal experience about cancer. This included the importance of connecting with individuals who themselves had not had cancer, but could relate and provide empathy. Participant 8 spoke about a neighborhood friend who was supportive to her, stating, 'I have a neighbor that was really concerned, and she talked to me, and she had a daughter that passed away with breast cancer. ... She'd have like little walks, or little healing services'. Not only were neighbors important, the support from other AI community and tribal members was significant. Participant 20 described this:

I think that, um, the Indian, Native community, we always feel at the bottom of some list. We're always the least educated, we're always the poorest, we're always the unhealthiest.

So I think that the Native community kind of can band together like that and support each other. I feel that.

However, some women identified the need for further support in this area and reported being frequently frustrated with the perceived lack of local sources of support while in care. Participant 34 reported:

None. We don't have a support system here. I wish there was. Like with American Indian women who are going through this because there is not a lot of support out here. I mean like I said since I've had it I can't talk to anybody around here about it because there isn't no support system out here. Like I said if you need to talk to somebody about it they'll refer you to Rapid City or they'll refer you to somewhere else to get counseled or to go talk to somebody.

For some participants, support and need for support from their community was especially important because of their shared history of oppression. Support from the neighborhood and community was reported as being important for many participants and as before, providing both emotional and instrumental support for participants.

Health practitioners

Finally, some women expressed the importance of the support provided by caring health practitioners. Participant 35 stated, 'My nurse midwife was great. She is very caring and then she's very understanding and she was very supportive'. Likewise, Participant 34 specified:

Who I really talked to was my doctor, [name of Dr.], before he passed ... I'd call to his clinic and the nurses would relay a message to him and if he's not busy he'll talk to me. If he's busy, he'll leave a message and call me back. So he was my support system, I mean through that clinic.

This support appeared to be instrumental, in that the health practitioners provided medical care for the participants, but also as important because of the emotional connection facilitated by these caring health providers. However, few participants reported receiving this support, high-lighting the important role of non-formal supports for women. Participants highlighted the importance of thoughtful and caring communication on the part of healthcare practitioners.

Discussion

Several interesting themes emerged across participants. Importantly, these findings were present across all types of cancer survivors (e.g. breast, cervical etc.), indicating that cancer type was not a salient difference related to types of social support. To begin, friendships were the most common form of non-family social support, followed by church support, community and neighborhood support, and support from health practitioners. Few women reported receiving substantial health practitioner support, emphasizing the importance of non-formal support systems for American Indian women with cancer. Moreover, women gained access to friendships, not only through personal and community connections, but through online forums. This may be particularly important for women residing in rural areas to find connection where access to in-person support services may be limited.

Further, despite women receiving support from a variety of sources, the forms of support were remarkably consistent. ‘Checking on’ women and ‘praying for’ women were mentioned for both friendships and church support as important. This differs from Bauer et al.’s (2005) finding that different types of support provide differing forms of social support (i.e. instrumental or expressive). Offering instrumental support through rides to a doctor’s appointment or providing meals made a difference for women. Instrumental support was provided by friends and church support, whereas for Bauer et al.’s (2005) study, this instrumental support was primarily offered by family. Offering emotional support, by letting women share their struggles with cancer was important, as well as offering companionship and fun through conversations, games, and get-togethers. Many of the support systems reported were regularly scheduled, such as support groups and church, indicating that the regularity of the meetings of support may be important. Finally, women also found support through non-cancer related support groups such as Alcoholics Anonymous. This was a surprising finding, and suggests that conventional conceptualizations of cancer support groups may need to be broadened, and that this support may take multiple forms.

Future research and limitations

Future research examining family support is needed. This qualitative study is not generalizable beyond its context. The focus of this qualitative study was to identify who and what types of support AI women cancer survivors reported. Though differences across participants with differing types of cancer were not found, future studies can replicate or extend this work with larger samples or quantitative studies. There is much heterogeneity across the 567 tribes and regions and across both urban and rural areas, and these differences need to be examined with regard to specific contexts (Bureau of Indian Affairs 2017).

Implications for social work practice

Several important implications can be drawn from these results. First, although the sources of support may differ, the forms of support provided was consistent. This can be an important point for health promotion. For example, community education programs and educational pamphlets can be created for distribution at churches or community centers, providing information on how people can further support cancer survivors. Specific support strategies were mentioned by survivors, such as ‘checking on’ the survivor, ‘offering prayer’ to those who practice a faith tradition, listening, offering to help with rides, meals and other daily needs, and doing fun things with survivors. These strategies can be infused into educational materials, which may be relevant across types of cancer, adapting the specific information to each cancer type accordingly. Women also reported finding support through non-cancer related support groups such as Alcoholics Anonymous. This was a surprising finding, and suggests that cancer screening, education, and support programs may need to be expanded to think beyond conventional arenas.

Additionally, since research shows that being isolated from one’s identity is understood to contribute to poor health, and Indigenous identity is often highly social, programs which facilitate building upon these social support networks may be more likely to be beneficial for, and desired, and well-received, by AI cancer survivors (King, Smith, and Gracey

2009). Several participants reported the importance of both their Native identity and their religious affiliation. Some possibilities for how social support programs could be expanded for AI women with cancer include the example of cancer programs that use a 'Native sister' model in which an AI women with cancer is paired with another AI 'sister' who provides emotional support throughout the cancer screening and treatment (Burhansstipanov 1998). This may be especially important since many participants reported not feeling support and connected to their community.

These results indicate that a diverse array of people make up the cancer survivor's support network, indicating the need for broad prevention programs that reach out to churches, a variety of community groups, and online forums. Online supports may be an important way to address the growing need identified for survivors in rural areas, and may provide ways for survivors in diverse geographic contexts to connect. These results suggest that social support can take multiple forms – and can come from both cancer related and more general social support systems. They also indicate that women frequently rely on non-formal support systems. Perhaps additional formal support systems should be developed to further supplement these non-formal systems. Survivors appear to benefit from both emotional and instrumental support from these sources. The roles that these supports play can be enhanced for sustainable community-based infrastructures that may be protective for cancer survivors.

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ORCID

Catherine E. Burnette  <http://orcid.org/0000-0002-1770-5088>

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