American Indian Women Cancer Survivors' Coping with Depressive Symptoms

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Abstract

Objective—Depressive symptoms have been identified as a primary predictor of quality of life among cancer patients. Depression and cancer are co-occurring and disproportionately elevated for American Indian and Alaska Native (AI/AN) women.. The purpose of this article is to examine American Indian (AI) women cancer survivors' coping mechanisms for depressive symptoms.

Research Approach—The methodology included a qualitative descriptive approach with conventional content analysis to examine the coping strategies of AI women cancer survivors associated with depressive symptoms. The interview guide was semi-structured and developed in collaboration with a community advisory board (CAB). Data-derived qualitative analysis was used to generate codes inductively from the data.

Participants—A sample of 43 AI women cancer survivors (*n*=14 cervical cancer, *n*=14 breast cancer, and *n*=15 other cancers) from the Northern Plains region, in the state of South Dakota were interviewed. Data were collected from June 2014 to February 2015.

Methodological Approach—Qualitative content analysis was used for data analysis, which allowed themes to emerge inductively from the data. Analysis revealed 430 preliminary codes. After de-briefing, validation, and discussion among co-authors, these were then sorted into 67 codes. Member checks with all available participants were conducted to minimize misinterpretation.

Findings—A total of 26 participants (62%) indicated they had feelings of depression since their cancer diagnosis. Women coped with depressive feelings by (a) participating in faith traditions; (b) seeking creative and positive outlets; (c) martialing family and social support; and (d) keeping busy with other life activities.

Interpretation—AI women experienced depressive symptoms following a cancer diagnosis and used a variety of positive coping mechanisms to create personal meaning.

Implications for Psychosocial Providers or Policy—AI women may need unique support following a cancer diagnosis, and interventions should incorporate AI beliefs and traditions, such as storytelling and talking with family and community members.

Keywords

Cancer; American Indian or Native American; women; depression; coping; health disparities; qualitative research

Background

Depression and cancer are both disproportionately elevated among American Indian and Alaska Native (AI/AN) women,[1–3] and tend to co-occur.[4,5] Depressive symptoms have been identified as the single most important predictor of quality of life among some cancer patients.[5,6] Yet, in-depth analyses of AI/AN women cancer survivors' coping practices surrounding depression are largely missing from existing research. This scarcity of research is concerning, given a trust responsibility by the United States (U.S.) government to be accountable for the health and well-being of members of the 573 sovereign federally-recognized tribes.[7] The purpose of this article is to examine American Indian (AI) women's coping with feelings of depression following a cancer diagnosis.

Depression among American Indian and Alaska Native Women Cancer Survivors

AI/ANs continue to experience pervasive health disparities as compared with the non-AI/AN U.S. population.[8] For example, cancer is the leading cause of mortality for AI/AN women, who experience this disease at 1.6 times the rate of whites.[9] Disparities include mental health disorders (including depression, suicide, alcohol and other drug (AOD) use and dependence, and posttraumatic stress disorder),[10,11] and AI/ANs, on average, reportedly experience severe psychological distress at a rate of 1.5 times that of non-AI/ANs.[10] While 6.7% of the non-AI/AN U.S. population experienced an episode of major depressive disorder in 2015, the rate for AI/ANs was 8.9%--a rate higher than any other single ethnicity. [1] Moreover, AI/ANs are 1.7 times more likely to commit suicide than the non-AI/AN population.[12]

When comparing AI/AN to non-AI/AN cancer survivors, social and psychological quality of life tends to be lower for AI/AN cancer survivors (though AI/AN spiritual quality of life may be higher).[13] Understanding these disparities and the source of depressive symptoms is important, since fear and misunderstandings about cancer can lead to poorer treatment outcomes and adherence.[14] Depressive symptoms may also be exacerbated by the long

history of exploitation and distrust that often exists between medical institutions and AI/AN people,[15] along with other ethnic minorities.[16]

Depressive symptoms are common among cancer patients.[5,17] Indeed, depression and cancer tend to co-occur, with depression among cancer patients being higher amongst AI/AN cancer patients, ranging from 8%–24% in comparison with 4% in the general population.[19] The severity of depression is exacerbated by increased pain and cancer symptoms.[4,18] Depression has been highly associated with certain types of cancer,[19] including breast cancer (1.5%–46%), pancreatic (33%–50%) and lung cancers (11%–44%).[20]

Co-morbid depression can exacerbate general health problems and negatively impacts well-being, while also increasing the mortality of cancer patients.[21,22] More resources and services tend to be required to meet the needs of cancer patients with depression.[23] Depressed patients tend to exhibit lower adherence to treatment regimens than non-depressed patients,[26,27] making the identification of specific coping practices related to AI/AN women cancer patients needed and warranted. Because service providers and interventions do not tend to be culturally sensitive for AI/ANs, depression tends to be inadequately, infrequently, and inappropriately identified and treated among AI/ANs, so statistics should be perceived with caution.[25] Parallel to findings for men and women in the general population, AI/AN women report higher depressive symptomatology than AI/AN men.[24] Thus, understanding AI female cancer survivors' coping strategies for depression is essential for practitioners providing care for this group.

Methods

Research Design

This research was part of an overarching study focusing on the beliefs and meaning, cultural aspects and quality of care,[28] religion/spirituality,[29] social support,[30] and quality of life among AI women cancer survivors. We used components of community-based participatory research (CBPR), primarily in the form of a community advisory board (CAB) (including leaders and health professionals serving the AI populations under investigation) who: (1) identified relevant community priorities and research concerns; (2) aided with recruitment and results dissemination; and (3) strengthened community outreach and engagement throughout the research process. The design for this research utilized a qualitative descriptive methodology, an inductive inquiry which provides a rich account of experiences in easily accessible language,[31] to examine AI women cancer survivors' coping with depressive symptoms. The key research questions that guided this study were:

1. How do AI women cancer survivors describe their experiences with depressive symptoms?

2. How did women cope with depressive symptoms throughout their cancer experience?

Qualitative description was chosen as it has been found to be especially useful in working with high risk populations and for understanding culturally specific attributes, as it

highlights the voices of respondents themselves rather than high level interpretations by researchers.[31]

Setting and Sample

This research was part of a collaboration with an eastern and western community-based health service site in the Northern Plains region, in South Dakota: (a) the Avera Medical Group Gynecologic Oncology located in Sioux Falls and (b) the John T. Vucurevich Cancer Care Institute, Rapid City Regional Hospital located in Rapid City. These are the two main medical institutions serving AI women in the eastern and western parts of South Dakota. The sample of 43 women included breast cancer, cervical cancer, colon cancer, and other types of cancer survivors (i.e., n=14 breast cancer, n=14 cervical cancer, and n=15 other cancers). Using purposeful sampling, inclusion criteria for participants were: (a) experiencing cancer of any type within the last 10 years; (b) completing cancer treatment with no symptoms of recurrence; (c) identifying as female; (d) being AI; (e) residing in the state of South Dakota; and (f) being an adult (ages 18 years and older).

Regarding participant demographic characteristics, ages of participants were between 32–77 years, with an average of approximately 56 years. In total, 97.7% of respondents had a high school degree or equivalent. Almost half (49%) of participants' household income per month was $1,499 or lower. About one-third, or 32.5%, indicated that their health was *poor/fair*, whereas, the remaining two-thirds, 67.5%, stated their health was *good/excellent*. Participant cancer-types included: breast (n=14, 32.6%); colon (n=5, 11.6%); cervical (n=14, 32.6%); Non-Hodgkin Lymphoma (n=2, 4.7%); lung (n=2, 4.7%); and others (n=6, 13.9%). Most respondents (n=39, 90.7%) described a religious affiliation. The majority (93%, n=40) reported having medical insurance of some kind. On average, participants reported having cancer a total of 2.42 years (SD=2.19).

Data Collection

Approval from the following Institutional Review Boards was provided before beginning data collection: (a) University of South Dakota, (b) Avera McKennan Hospital, (c) Rapid City Regional Health, and (d) Sanford Research Center. Participants completed voluntarily signed consent prior to study enrollment. An author and two extensively trained assistant researchers conducted the interviews. Recruitment efforts included mailing fliers to cancer survivors at the two health service sites, posting fliers at community agencies, newspaper and public radio announcements, and word-of-mouth at local agencies and/or churches. Data were collected where participants preferred (e.g., participants' homes, religious sites, a private conference room at the health service site, or the principal investigator's office) from June of 2014 to February of 2015.

The interview guide was semi-structured and developed in collaboration with the CAB, who reviewed the guide in its entirety and ensured the cultural relevance to AI women cancer survivors. During the interview, participants were asked questions, such as, "Have you had feelings of depression since your cancer diagnosis and treatment? In your opinion, what made you feel this way?" And (if relevant), "When you felt depressed, how did you cope with the feeling?" The entire interview guide has been included in Appendix A. Graduate

students transcribed verbatim the audio-recorded interviews. These ranged from half an hour to two hours in length. Participants were provided $50 for their time and a gift card for travel expenses. Transcribed interviews were analyzed using NVivo software.[32]

Data Analysis

Data-derived qualitative analysis is encouraged for qualitative descriptive studies,[31,33,34] as it generates codes inductively from data.[34] Thus, we used the conventional approach to content data analysis, which focuses on emergent themes in the data, rather than directed (i.e., using pre-determined codes) or summative content analysis (i.e., counting codes).[35] Conventional qualitative content analysis is well-suited to qualitative descriptive studies,[31,33] allowing for inductive themes to emerge directly from the data.[33] After the 2nd author sorted data into sub-sections by respective interview guide questions, the first author conducted the initial steps of data analysis. This included: (a) immersion in the data through listening to interview recordings and reading through interview transcripts multiple times to understand data more deeply; and (b) line-by-line coding of data and writing notes to capture key themes and ideas. A total of 430 preliminary codes or *meaning units* (for the overall study) were identified through this process, which were then sorted into broad categories with subcategories. Codes associated with this article included 67 codes across 43 participants, with 395 excerpts coded. To explore whether any significant differences existed across cancer types, co-authors discussed and validated clusters and subcategories. No differences were identified. The 2nd author and remaining authors expressed no disagreements in overarching themes and reviewed coding schemes and the descriptive summaries of each theme with supporting quote. Then, categories arrived at inductively arrived were used to organize themes into meaningful groupings. These groupings, with their associated quotes, were provided to participants for member checking. Authors invited all participants to participate in member checks as many as three times. Over half (*n*=23, 53.5%) participated in this process. However, close to half (*n*=21, 46.5%) were not reachable because they had disconnected phones. Participants did not request any changes or amendments. Milne and Oberele's (2005) rigor strategies were used, which are specific to qualitative descriptive studies.[33] These strategies include: (a) *authenticity* to the goal of the research study; (b) *credibility,* or trustworthiness of results; and (c) *criticality,* or intentional decision-making processes. We prevented bias by engaging in peer review across co-authors, ensuring study integrity.[33]

Results

Many participants (*n*=26, 62%) reported feelings of depression since their cancer diagnosis. These feelings often related to changes in social roles and relationships. Participant 33 indicated that she felt loss due to losing her ability to have more children, stating,

> At first, I got depressed, and then I felt like really sad because I wasn't able to have any more babies, and I felt that I was cheated [clears throat], and it still bothers me sometimes. [clears throat]

Participant 33 went on to indicate how she initially coped with her cancer:

Just after I had it [cancer] I, you know, felt depressed at times, and I'd go find someone to talk to about it. There were times when I would just sleep, just stay in my room, make my room dark and just sleep through it. And I don't know how really exactly how long that lasted, but it wasn't too long afterwards because like I said I would drink, you know, just to deal with it, use alcohol to deal with it.

Participant 13 also reported using alcohol to cope with depressive symptoms brought about by cancer:

I drank alcohol. I'm in recovery now. But I would drink it to numb the pain and to forget about it. But then when I would get really gassed and I would cry a lot, I would relive the memories and not let it go.

She went on to describe her symptoms:

I didn't like to visit with people; I didn't…like I wanted to be by myself. And I'd get grouchy, you know? I didn't mean to, you know? I just wanna push everybody outta my way, get outta my face, things like that…whoever come[s] visit, I'll go in my room and shut the door until they left and I'd come out.

However, one-third (*n*=14) of people indicated they did *not* feel depressed in their cancer survival experiences. As Participant 29 expressed, "No," and added, "I have all these books to help me with anything I go through." Participant 28 recalled:

I haven't really struggled with depression because I feel really fortunate to be alive and to be able to share my experience, and I think the only part of my breast cancer diagnosis and treatment, the only time I felt depressed is when I lost my hair.

Participant 12 explained:

No, huh-uh. Like I said, I couldn't believe it at first, but I got used to it. I just, I don't have no depression or anything. I can't afford it, you know? I got my grandkids, they come and keep me company and stuff, or they call me all the time, you know and it's good.

Coping with Depressive Feelings

Women coped with depressive feelings by (a) participating in faith traditions; (b) seeking creative and positive outlets; (c) martialing family and social support; (d) keeping busy with other life activities; and (e) often using a combination of these strategies. The focus now turns to these coping strategies.

Participating in Faith Traditions.—When people had feelings of depression, 64% (*n*=27) described a variety of ways they coped with such feelings. Some participants practiced AI/AN spiritual traditions. Participant 15 stated:

I burn the sage, the sweet grass. And like the smell of it just makes me feel calm. … I just kind of like meditate, and … the pain or whatever goes away. … I use that for the depression for mainly too now. Just that, for the relaxing. Sometimes my brain just [makes noise] goes a hundred miles an hour.

Others sought comfort through a combination of traditional spiritual practices and formal religious affiliation. Participant 34 added:

> I go to church. I, we go every Sunday. We have a little country church …. So then I go to church and then also there are days when I feel, if I feel lonely or feel depressed then I will get my smudge bowl out and I pray for myself and ask the Creator to help me with whatever is bothering me and so then in church [spiritual leader] always likes to use like sweet grass and stuff.

When asked how she coped, Participant 18 mentioned, "You wouldn't believe this, prayers. I pray a lot. And I'm not kidding you, prayers really help me. It really does." Likewise, Participant 28 reported prayer as one way she dealt with depressed feelings: "I talked to friends and I prayed, and I would just listen to Christian music and that would always help." She added:

> I feel like a lot of my Christian friends encouraged me by telling me they were praying for me. I believe that there is a lot of feeling in your hair, and I think that's kind of why I felt bad that I lost my hair because but at the same time it was kind of, in our [community we] believe when you're mourning something you cut your hair. That belief that you cut your hair or you lose your hair kind of helped me go with it because there was cancer in my hair, I think, so whenever I lost my hair it was okay because in our culture, we believe that has a lot of feeling and that helped me let go of my hair.

While some participants let out their feelings through prayer, expressing emotions was another outlet for dispelling depressive symptoms. As Participant 10 described:

> I just cried. I cried and told myself things would get better. Things would turn out more [*sic*] bette Sometimes I prayed to the Lord to not to let me be so depressed. I don't like to be depresse…

Seeking Creative and Positive Outlets.—Many participants described doing activities they enjoyed or seeking a creative outlet as a way to deal with their depressive symptoms. Participant 5 related, "I just go outside and get a breath of fresh air and you know talk to somebody on the phone like my mother." Participant 9 described, "If I started feeling sad or whatever, I'd go in, sit down or whatever and play the piano. That was my outlet." She added, "I do A LOT of reading, LOTS. I think I read 30 novels." Participant 8 reported, "I'll go find something to do or go play umm, play with my grandkids…" Participant 24 expressed, "I try to find something to do. Something creative that I can put the feelings into." She added what was most helpful, indicating: "It's a combination of doing my artwork and praying at the same time. Um, I like to get into my artwork and while I'm doing that it's able to clear my mind and focus on something else." Some people turned to faith and exercise, as Participant 31 related, "I prayed, and I ran." Finally, Participant 19 also recommended helping others:

> I think the only thing that I could really hold onto was that sometimes when things happen to you in life, that there's a reason why they do. And that it's not just that

you've had breast cancer, it's like, that you learn from it, and that you have to help others. To me, mine is all about helping others.

Martialing Family and Social Support.—Family relationships were indispensable when it came to women feeling supported and finding meaning amidst their cancer experiences. Participant 35 explained, "I did [feel depressed] at first, but I always tried to think positive. I tried to think positive and I'd just pray and I'd try not to let too many things get me depressed." When she felt down, what she felt was most helpful was:

Being around my kids, my husband. It was helpful to see my kids smile, to see them laugh, to see them, you know, get hugs and kisses from them.

Participant 28 went on to relate how her husband supported her:

I think especially because my husband helped me through, I mean he saw me before I was diagnosed with cancer and after I was diagnosed and to see me with hair and to see me without hair, for him to say that I was still beautiful.

Staying Busy.—Some participants felt distraction was helpful, as Participant 41 explained, "Watch TV to get my mind off of it. I really don't like to talk about it, you know, because there's not nothing nobody could do, but when I do I just talk to [partner] because he's the one that's always right there." Participant 20 also stated, "Keep busy … Keep busy and pray. …And be satisfied, give gratitude you know, and reach out to other people." Participant 30 explained,

I guess I didn't really know how to deal and cope. I would just stay busy with my children and take them out to their activities… Or, be visiting with them one day, to have someone come to the school with them and different things. Um, I just let them, let myself be absorbed in them. And stayed in church, and all of that.

Conclusions

Cancer survivors are exposed to a myriad of situations and challenges that require incredible strength to withstand. Understandably, results reveal that depressive feelings were experienced by the majority (62%) of participants after cancer diagnosis. Challenges related to the patient's abilities to continue important life activities (e.g., have more children) tended to cause significant levels of depressive symptoms for many women. Some women turned to alcohol to cope with the emotional distress of their cancer experiences. Yet, a third of women also reported not experiencing depressive symptoms, indicating they found meaning through their faith and family, which may have buffered against depressive symptoms.

Women coped with depressive feelings in a number of ways, namely participating in faith traditions, seeking creative and positive outlets, martialing family and social support, and keeping busy with other life activities. Though not yet examined with AI/AN women, a meta-analysis examined religion and spirituality as they relate to the mental health of cancer survivors.[36] Robust findings indicating the positive effect of religion and spirituality on the mental health of cancer survivors, along with specifically buffering against depression were reported; however, the ethnic and cultural specificity of how women experience and practice

faith traditions was not part of this inquiry. Women participated in both AI/AN spiritual traditions, such as burning sage and sweet grass and meditating, as well as formal Christian religious institutions. Prayer enabled them to cope with feelings of loneliness by making them feel connected, and often provided an outlet for them to express overwhelming feelings. In addition, friends from faith communities frequently provided much encouragement. Many women sought out positive activities to channel their emotions and offset their depressive symptoms, through spending time outside, playing music, reading, spending time with friends and family, doing artwork, and helping others. Family and social support were instrumental to women, providing the love and validation women needed in moments of vulnerability. Staying active and keeping busy was also protective, and reportedly kept women out of negative thought patterns. All of these strategies were integral to AI women cancer survivors coping with their cancer experiences.

Study Limitations and Future Research

Several limitations of the present study should be recognized. First, these research findings were derived from self-reports, which are a potential source of bias. In addition, the sample only includes AI women from South Dakota, and therefore, should not be generalized to AI women in other regions. This article focuses primarily on positive coping strategies, yet some women did report coping through the use of alcohol. This indicates that separate inquiries that investigate negative coping may be warranted to glean important information about coping strategies – both constructive and less constructive forms. It is also possible that some participants may have found some questions to be leading, such as: "Has your family been supportive?" Through following the rigorous analytical processes described in the methods section, this concern has hopefully been minimized.

Future research examining AI perceptions of coping with cancer and depression—in the general population, and for specific AI groups across a variety of regions – is needed for more nuanced understandings of cancer survivors' needs following a cancer diagnosis. The unique stressors experienced by AI women make an analysis of coping behaviors particularly important. Considering the history of medical exploitation and limited access to services, research which highlights protective factors and that uses a resiliency and strengths-based perspective is especially needed.[37,38] Although some qualitative research has identified coping mechanisms for managing depressive symptoms in cancer patients parallel to those identified here, such as coping through faith, social support, thinking positive, and using avoidance based strategies, this limited research did not report the ethnic identity of cancer survivors.[39] More research on ethnic minorities, comparing AI/AN populations with other women is needed. This qualitative study is not generalizable beyond its setting. Although no differences were found across participants with distinct cancer types, future research may further explore whether cancer type affects how individuals cope with cancer. Finally, distinctions need to be examined across AI/AN contexts, and cancer coping experiences and practices may vary considerably by tribe and region.

Clinical Implications

A severe life-threatening illness, like cancer, can challenge an individual's sense of self. For AI female cancer survivors, depressive symptoms were common among cancer patients,

consistent with previous research.[17,40] Depressive symptoms affect the quality of life of cancer patients and their health care outcomes.[6] Focusing on family and other important social relationships is an area where many individuals can find refuge from depressive symptoms following a cancer diagnosis.[37] Health professionals may consider incorporating family in their patient's treatment.[37] For AI/AN persons, sources of support may include a spiritual or faith healer.[14] Previous research has documented the ways that AI/AN identity impacts women's health-care decisions, with those with stronger connections to their identity often having more positive health-behaviors.[40] However, for many individuals, their AI/AN identity could also be an additional source of distress if they perceive their doctors to be racist, judgmental, or non-supportive of traditional treatments or beliefs.[40] Some AI women and men with depressive disorders are more likely to consult traditional healers than medical professionals about their treatment,[41] utilizing both informal and formal supports.

Informal or culturally-based sources of support are particularly salient for AI cancer survivors given the chronic historical oppression (chronic oppression introduced through colonization and perpetuated through continued marginalization)[42] and inadequate medical and mental health service programs that exacerbate the health inequities they experience. [15,40,43,44] Moreover, given this historical oppression, AI cancer patients tend to have ambivalent feelings about seeking help from services that are not culturally relevant or culturally tailored.[15,40,42–46] Research indicates that patients may not feel comfortable discussing medical and mental health issues with providers who are perceived to be disrespectful of or unwilling to incorporate culturally specific practices into their work.[45] The results from this study indicate that AI women experienced depressive symptoms following their cancer diagnosis, often related to challenges and changes in their identity and social roles. These findings also indicate that AI women use a variety of positive coping mechanisms to adapt to these changes, often focusing on activities that create personal meaning, or that strengthen social and familial relationships.

Acknowledgments

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