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American Indian Women Cancer Survivors' Perceptions and Experiences with Conventional and Non-Conventional Mental Health Care for Depressive Symptoms

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Abstract

Background—Despite cancer and depression being disproportionately high for American Indian and Alaska Native (AI/AN) women, such cancer survivors' help-seeking practices and perceptions related to depression are absent in extant research. A broader context of historical oppression has set the stage for unequal health outcomes and access to quality services. The purpose of this article was to explore AI women cancer survivors' experiences with conventional mental health services and informal and tribally-based assistance, as well as barriers related to mental health service utilization.

Methods—A qualitative descriptive study methodology, with qualitative content analysis, was used to examine the experiences of AI women cancer survivors as they related to help-seeking experiences for depressive symptoms. The sample included 43 AI women cancer survivors ($n=14$ breast cancer, $n=14$ cervical cancer, and $n=15$ colon and other types of cancer survivors).

Results—Since receiving a cancer diagnosis, 26 (62%) participants indicated they had feelings of depression. Some participants ($n=13$) described mixed perceptions of the mental health service system. Generally, participants viewed families and informal support systems as primary forms of assistance, whereas conventional services were reported as a supplementary or “as needed” forms

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of support, particularly when the informal support system was lacking. Participants received help in the forms of psychotropic medications and psychotherapy, as well as help from family and AI-specific healing modalities (e.g., sweat lodges and healing ceremonies). Stigma and confidentiality concerns were primary barriers to utilizing conventional services as described by 12 (29%) participants.

Discussion—Participants' help primarily came from family and tribally-based entities, with conventional mental health care being more salient when informal supports were lacking. The mixed perceptions espoused by participants may be related to a broader context of historical oppression; family and social support and tribally-based services may be protective factors for cancer survivors with depression.

Both cancer and depression rates are disproportionately high for American Indian and Alaska Native (AI/AN) women (The National Institute of Mental Health 2015; Beals et al. 2014; Espey et al. 2007, 2119–2152) The National Institute of Mental Health 2015) and are likely to co-occur (Spiegel and Giese-Davis 2003, 269–282). Yet, AI/AN women cancer survivors' help-seeking practices and perceptions related to depression are absent in extant research. This absence of research focused on ameliorating such health disparities is quite problematic, given the trust responsibility (based on treaty agreements between sovereign tribes and the U.S. government) to provide for the health and well-being of the members of the 567 federal sovereign tribes (U.S. Commission on Civil Rights 2004; Bureau of Indian Affairs 2018). Such disparities are representative of continued historical oppression experienced by AI/ANs (Burnette and Figley 2017, 37–44). Without research uncovering factors related to help-seeking for depression among AI/AN women cancer survivors, progress to eradicate such disparities is out of reach. Moreover, knowledge of help-seeking practices related to depression may improve AI/AN women's adherence to their medical regime, expand clinical opportunities—both conventional and informal or tribally-based, inform extant interventions, and improve clinical outcomes.

In comparison with the general U.S. population, AI/AN persons continue to experience persistent health disparities (U.S. Commission on Civil Rights 2004). One of these disparities is cancer, which is the principal cause of death among AI/AN women (Espey et al. 2014, S303-S311). AI/AN women have cancer at a rate that is more than one and a half times that of White women (Espey et al. 2014, S303-S311). These disparities extend to mental health, and AI/ANs have been found to experience serious psychological distress at 1.5 times the rate of the general population (American Psychological Association 2010), with elevated levels of depression, substance abuse and dependence, posttraumatic stress disorder, and suicide (American Psychological Association 2010; Gone and Trimble 2012, 131–160; Sarche and Spicer 2008, 126–136). Indeed, although 6.7% of the general adult U.S. population experienced a major depressive episode in 2015, the rate for AI/ANs was much higher at 8.9%—higher than all other ethnicities except those with multiple ethnic backgrounds (The National Institute of Mental Health 2015). Data from the 2001–2002 National Epidemiological Survey on Alcohol and Related Conditions indicate that AI/AN men reported experiencing major depressive disorders at approximately 1.6 times the rate of non-Hispanic white (NHW) men, whereas the differences between AI/AN and NHW women were not statistically significant in this sample (Brave Heart, Maria Yellow Horse et al.

2016, 1033–1046). Thus, depression rates tend to vary by gender. Finally, AI/ANs are 1.7 times more likely to attempt suicide than the general U.S. population (Indian Health Service 2017).

Cancer incidence and death rates also vary by cancer type and gender (Plescia et al. 2014, S388-S395). For example, incidence rates for both kidney and colorectal cancers, are higher for AI/AN men and women than for whites, but AI/AN women experience higher incidence and death rates than AI/AN men or white women (Perdue et al. 2014, S404-S414). Though lung cancer rates have been decreasing for AI/AN men, for AI/AN women these rates have been increasing (Plescia et al. 2014, S388-S395). Since the prevalence and type of cancer varies by gender, it is essential that the experiences of AI women cancer survivors be specifically explored.

Depression and cancer frequently co-occur, and the intensity of depression may increase depending on patient pain and cancer symptom severity (Spiegel and Giese-Davis 2003, 269–282). Co-morbid depression is associated with a significantly increased risk of death, negatively impacting the general health and well-being of cancer patients (Onitilo, Nietert, and Egede 2006, 396–402; Moussavi et al. 2007, 851–858). Cancer patients with depression also tend to require more extensive resources utilization than those without depression (McLaughlin et al. 2006, 1187–1193). Congruent with national trends where women are at higher risk for depression (Weissman et al. 1993, 77–84), research on the prevalence of depression among AI women suggests that AI women are at higher risk than men (Beals et al. 2005, 99–08; Beals et al. 2014).

Additionally, compared to patients who are not depressed, depressed patients are less likely to adhere to medical treatment regimens (DiMatteo, Lepper, and Croghan 2000, 2101–2107), making the need to understand the specific needs and perceptions of AI women cancer patients with depressive symptoms highly needed. The purpose of this article was to use the culturally grounded Framework of Historical Oppression, Resilience, and Transcendence (FHORT) to explore AI women cancer survivors' perceptions of conventional mental health services, their experiences with conventional, along with informal and tribally-based mental health assistance, and barriers related to mental health service utilization (Burnette and Figley 2017, 37–44). The FHORT (Burnette and Figley 2017, 37–44), proposes that historical oppression has set the stage and contributed to the health inequities experienced by AI people. However, resilience and transcendence have also been continually demonstrated among such populations, despite experiencing chronic adversity (Burnette and Figley 2017, 37–44; Goodkind et al. 2012, 1019–1036). The FHORT (Burnette and Figley 2017, 37–44) works from the recommended non-linear, relational worldview—encompassing the context, mental, physical, spiritual, and emotional realms of wellness—proposed by AI/ANs scholars (Burnette and Figley 2017, 37–44; Fleming and Ledogar 2008, 7–23).

Prevalence of Depression among Cancer Patients

Although the overall treatment of cancer has generally improved, resources and protocols for the treatment of co-morbid mental health disorders among those with a cancer diagnosis is

still greatly needed (Walker and Sharpe 2009, 436–441). Depression, one of the more commonly researched mental health disorders among patients with cancer, is often difficult to diagnosis because of the broad range of symptoms that can apply to its possible diagnosis (Massie 2004, 57–71). Diagnosis of depression among cancer patients varies greatly depending on the symptoms used for diagnosis, the type of cancer, and study population, but depression is generally much higher among cancer patients than among the general population (Massie 2004, 57–71). Female cancer patients are more likely to experience depression, with one study finding that female cancer patients were twice as likely to experience clinical levels of depression as males (16.4% v. 8.6%) (Linden et al., 2012).

There is little research documenting the prevalence of co-morbid depression among AIs with cancer. Depression is one of the most common mental health disorders in AI communities, although its identification and treatment has seldom received much attention (Garrett et al. 2015, 227–236). There is evidence that depression may often be inadequately, inappropriately, or infrequently diagnosed and treated among AIs (Armenta et al. 2014, 1347–1355; Whitbeck et al. 2002, 400–418), representing not only a failure to uphold treaty agreements (U.S. Commission on Civil Rights 2004; Bureau of Indian Affairs 2018), but a continued form of historical oppression through inadequate healthcare (Gone and Trimble 2012, 131–160). These findings make the exploration of depression among AI female cancer survivors especially needed and have important implications for medical and mental health professionals treating this group.

Treatment of Co-Morbid Depression

Despite the importance of addressing comorbid depression, its treatment in cancer patients has often been found to be inadequate (Spiegel and Giese-Davis 2003, 269–282). Even with evidence showing that mental health treatment may decrease depression and the experience of pain, while potentially increasing survival time, mental health treatment is often underutilized for cancer patients (Spiegel and Giese-Davis 2003, 269–282). Among the general U.S. population, this underutilization of depression treatment among cancer patients has been attributed to a variety of factors, including difficulties in correctly diagnosing depression, family reluctance to acknowledging the depression, and the constraints of patient care (Fisch 2004, 105–111). There are also gender differences reported in the need for psychological support among cancer patients, as men with cancer have been identified as feeling less informed overall about psychological support, though they also generally express fewer mental health support needs (Faller et al., 2005). Given the distinct history of historical oppression, culturally specific factors may exacerbate this already tenuous area of healthcare. The focus now turns to the FHORT to investigate this further (Burnette and Figley 2017, 37–44).

The FHORT: A Brief Overview

Because this framework is described in-depth elsewhere (Burnette and Figley 2017, 37–44), we briefly describe it here as it relates to the current research on help-seeking for AI women cancer survivors – namely introducing the concept of historical oppression, resilience, and well-being within this framework. Historical oppression is broader, but inclusive of

historical traumas (e.g., forced relocation, boarding school, land dispossession, religious suppression); it extends historical trauma to include proximal stressors in the forms of chronic poverty, discrimination, and marginalization, which are intricately connected to the health inequities experienced by AI peoples (Burnette and Figley 2017, 37–44; Wexler 2014, 73–92). Historical oppression poses a significant adversity for AI/AN people, and their continued act of survival and continuance demonstrates resilience.

Western and AI/AN notions of health and mental health differ. AI/AN peoples tending to view historical oppression and the devastating, chronic, and intergenerational disruptions in cultural practices brought on by colonization, as driving negative physical, social, and behavioral outcomes. This is in contrast to more isolated and compartmentalized views of health in conventional approaches, which tend to examine distinct health or mental health outcomes in isolation (Brady 1995, 1487–1498; Burnette 2015a, 1–20; Burnette 2016, 354–368; Burnette 2015c, 531–563; Burnette and Figley 2017, 37–44; Duran et al. 1998, 95–113; Gone and Trimble 2012, 131–160).

Factors, such as racism, poverty, loss of land, language, environmental deprivation, and emotional and spiritual disconnection are thought to be AI/AN factors related to health disparities (Burnette and Figley 2017, 37–44; King, Smith, and Gracey 2009, 76–85). Because AI/AN identity is inherently social, being isolated from one's identity is believed to contribute to poor health (King, Smith, and Gracey 2009, 76–85). Indeed, as Kirmayer et al. (p. 63) stated, historical oppression has taken the form of “deliberate human actions and policies aimed at cultural suppression, oppression, and marginalization” (Kirmayer et al. 2011, 84–91). Historical oppression has resulted in widespread disruption in families and communities, undermining parent socialization, expressions of emotional warmth, AI identity, and the transmission of values, language, and traditions (King, Smith, and Gracey 2009, 76–85). Thus, rebuilding this connection is needed for the repair of the negative effects of such oppression (Mohatt et al. 2011, 444).

Resilience and Well-being.

Resilience is generally characterized as positive adaptation, despite experiencing significant adversity (Fleming and Ledogar 2008, 7–23). Resilience can occur across individual, familial, community, national levels, and beyond (Kirmayer, Sehdev, and Isaac 2009, 62). The FHORT focuses on well-being as a primary outcome of interest (often termed as wellness) (Burnette and Figley 2017, 37–44), which integrates mind (i.e. mental and emotional health) and body (i.e., physical health) in a holistic approach to disease prevention and health promotion (Centers for Disease Control and Prevention (CDC) 2016). This is commensurate with AI/AN notions of health and wellness, which also tend to view persons living harmoniously with their environment, related to the balance of physical, social, emotional, and spiritual elements (Brady 1995, 1487–1498; Hodge, Limb, and Cross 2009, 211–219; King, Smith, and Gracey 2009, 76–85; Kirmayer, Sehdev, and Isaac 2009, 62). Balance extends beyond the individual to include living in harmony with the community, others, and the spirit world (Hodge, Limb, and Cross 2009, 211–219; King, Smith, and Gracey 2009, 76–85).

Notions of health for AI/AN people tends to clash with non-AI/AN notions (i.e., isolating and treating disease, health being seen only as the absence of disease) (King, Smith, and Gracey 2009, 76–85). Sickness, in the AI worldview, is the absence of wellness, or an imbalance, and connections to family and relations are essential to wellness (King, Smith, and Gracey 2009, 76–85). Well-being, or wellness, includes people's perspectives on how their 'whole' life is going, including life satisfaction (Centers for Disease Control and Prevention (CDC) 2016). According to the CDC (2016), well-being, at minimum includes positive emotions, the absence of negative emotions (e.g., depression and anxiety), and satisfaction with life, along with feeling healthy and good. It can encompass physical, economic, social, developmental, emotional, psychological, life satisfaction, and employment domains (Centers for Disease Control and Prevention (CDC) 2016). Congruent with the FHORT (Burnette and Figley 2017, 37–44), this research sought to explore the following research questions: (a) "How do AI women cancer survivors perceive conventional mental health services (i.e., perceived helpfulness)?" (b) "What are AI women cancer survivors' experiences with formal and informal (i.e. social support) and tribally-based mental health assistance? What forms of help did they receive and from whom?" and (c) "What are AI women cancer survivors' perceived barriers to seeking conventional mental health services?"

Conventional Approaches to Mental Health Treatment

Among conventional forms of treatment, therapeutic elements are typically geared toward the outcome of interest (i.e., depression), and broader factors, such as spiritual health or positive social interactions are typically not focal. Drug treatment is often the first approach taken to addressing co-morbid depression (Rosenstein 2011, 101–108; Fisch 2004, 105–111). In a systematic review investigating treatment of depression among cancer patients, few rigorous studies focused solely on the use of psychotherapy for treatment of co-morbid clinical depression (Fisch 2004, 105–111). This dependence on drug treatment occurs despite findings from systematic reviews that the use of cognitive behavioral therapy (CBT), for treatment of depression among cancer patients (identified in 15 studies), was effective at treating depression, anxiety, and improving overall quality of life (Osborn, Demoncada, and Feuerstein 2006). However, most studies that include a psychological therapy component (psycho-educational interventions, CBT, interpersonal therapy or problem-solving therapy) combined it with the use of medications, and far more research explores the impact of medications on the treatment of depression among cancer patients (Fisch 2004, 105–111; Pirl 2004, 32–39). In large randomized control trials (RCT) comparing the use of medications compared to the use of a placebo, there is a slight trend supporting the use of medication in treating co-morbid depression (Fisch 2004, 105–111).

The effect of psychosocial interventions on the treatment of cancer among this group appears to be small (Pirl 2004, 32–39). There is some evidence that group therapy and short, but intensive interventions, may be as effective as longer, individual therapy (Sheard and Maguire 1999, 1770–1780). Higher effect sizes were found for the use of a combined psychosocial/medication intervention, and even higher for the use of antidepressants in treating co-morbid depression (Pirl 2004, 32–39). Anti-depressant medications were those most commonly used to treat co-morbid depression (Pirl 2004, 32–39). No RCTs or

alternative or complementary treatments for depression among people living with cancer could be identified (Fisch 2004, 105–111; Pirl 2004, 32–39), making it unclear the extent to which informal (i.e. social support) and tribally-based assistance may be used, along with their effectiveness.

Depression Treatment in AI Communities

More congruent with the well-being approach to health, help-seeking in AI communities is often characterized by a use of a mixture of both formal along with informal (i.e. social support) and tribally-based assistance, and which can vary by tribe (Beals et al. 2014; Buchwald et al. 2000, 562–564). Among some tribes, women and men with depressive disorders are more likely to consult traditional healers than medical professionals about their treatment (Buchwald et al. 2000, 562–564), highlighting the need for research on both conventional and informal or tribally-based sources of support for mental health care.

The importance of informal or tribally-based sources of support may be especially important for AI cancer survivors because of the long history of inadequate mental health and social service programs, which have served to exacerbate health disparities (Canales 2004b, 18–44; Canales et al. 2011, 894–911; Garrett et al. 2015, 227–236; Canales 2004a, 411–435). Additionally, because of the long history of oppression experienced by AIs, some cancer patients may have ambivalent feelings about seeking help from these conventional services (Canales 2004b, 18–44; Canales et al. 2011, 894–911; Garrett et al. 2015, 227–236; Broome and Broome 2007, 161–173; Canales 2004a, 411–435; Burnette and Figley 2017, 37–44; Burnette 2015c, 531–563). This ambivalence may extend to patients not feeling like they can discuss their mental health problems with their provider because of the history of medical practitioners not respecting or being willing to incorporate traditional practices into their work (Broome and Broome 2007, 161–173). Indeed, as noted by Walters and Simoni (2002), the health problems of AI/AN women are uniquely impacted by the history of colonization, continuing poverty, and discrimination. AI women are also vulnerable to the views of medical and health practitioners, social service providers, and researchers who often pathologize their well-being and perpetuate a paternalistic view of health and well-being (Walters and Simoni 2002, 524–524). Thus, it is necessary to explore the culturally specific perceptions, experiences, and identified mental health barriers of AI women cancer survivors specifically.

Methods

Research Design

Through the use of a community-based participatory research approach (CBPR), a community advisory board (CAB) comprised of AI community leaders and health care professionals who practice in the respective AI communities involved in this research was created. The primary duties of this CAB included: (1) identifying community needs and concerns as they related to research; (2) directing the recruitment of participants and the dissemination of results; and (3) facilitating community support and involvement in the research project. Because of its ability to provide a rich and in-depth account of participants' experiences in understandable and every-day language, we used a qualitative descriptive

study methodology, which is a naturalistic and inductive form of research inquiry (Sullivan-Bolyai, Bova, and Harper 2005, 127–133). We used this approach to examine the experiences of AI women cancer survivors as they related to help-seeking experiences for depressive symptoms. Qualitative description is appropriate because it facilitates understanding cultural nuance and sensitivity when working with vulnerable populations since it prioritizes the voices of participants themselves in contrast to the often highly-abstract and detached interpretations of researchers (Sullivan-Bolyai, Bova, and Harper 2005, 127–133). Qualitative description is considered a “a fine-tuned research design” because it avoids these abstract interpretations and aims at producing knowledge which is relevant to real settings and contexts, such as what role mental health plays in AI women’s cancer experiences (Sullivan-Bolyai, Bova, and Harper 2005, 127–133).

Setting and Sample

This study was developed and conducted through a collaboration with the following community-based hospitals: (a) the Avera Medical Group Gynecologic Oncology in Sioux Falls, South Dakota and (b) the John T. Vucurevich Cancer Care Institute, Rapid City Regional Hospital in Rapid City, South Dakota. Table 1 summarizes sociodemographic information. The sample of participants in this research was 43 AI women cancer survivors ($n=14$ breast cancer, $n=14$ cervical cancer, and $n=15$ colon and other types of cancer survivors). We were inclusive of different forms of cancer in this study so that we could assess the key help-seeking practices associated with depression that were present across types. Purposeful sampling, which determines who is best able to answer the central research questions (i.e., AI women cancer survivors) was used. We also used this method to determine at what point the data achieved *saturation* (i.e., when no new meaningful information/redundancy is gained) (Sandelowski 1995). Inclusion criteria for study participation required: (a) personally experiencing any type of cancer in the last 10 years; (b) having completed all cancer treatments without signs or symptoms of cancer recurrence; (c) being female; (d) being 18 years or older; (e) being a resident of South Dakota; and (f) AI identification.

Participant ages ranged from 32 to 77 ($M=56.33$ years, $SD=12.07$). Educational attainment was relatively high, with 97.7% ($n=42$) of study participants having obtained a high school degree/GED. Around half ($n=21$, 49%) of participants reported a monthly household income that was less than \$1,499. Although 32.5% ($n=14$) of participants described their health as *poor/fair*, 67.5% ($n=29$) described their health as *good/excellent*. The types of cancer participants reported having 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%). Most respondents (93%, $n=40$) had some form of medical insurance and most described having a religious affiliation ($n=39$, 90.7%). For participants, the average length of time participants had cancer was approximately 2.42 years ($SD=2.19$).

Data Collection

Before beginning data collection, approvals from the Institutional Review Boards of the following institutions were obtained: (a) University of South Dakota, (b) Avera McKennan Hospital, (c) Rapid City Regional Health, and (d) Sanford Research Center. Prior to entering

into the study, all participants first signed voluntarily consent forms. The third author, the principal investigator (PI) of this study, and two research assistants who were extensively trained with backgrounds working with AI individuals and cancer survivors administered the interviews. To recruit participants for the study, fliers were sent to the two hospitals and were posted at community sites, announcements were made in the newspaper and on public radio, and word-of-mouth recruitment was utilized at local community agencies and churches. Interviews were conducted in the locations that participants' preferred (e.g., participants' homes, a private room at a community church, at the hospitals, or at the PI's office) from June 2014 to February 2015.

The semi-structured qualitative interview guide emerged through partnership with the CAB (see Table 2) and was developed following the community concerns and research needs identified by the CAB. The CAB reviewed the guide, making sure that the wording and meaning of each question was culturally appropriate and ensuring that the questions were culturally relevant for AI women cancer survivors. These questions included inquiries such as: "Have you ever sought help for depression? Do you think providing mental health services would help? Why or why not?" The interviews were audio-recorded and then graduate students transcribed the recorded interviews verbatim. These interviews ranged from 30–120 minutes. Participants were compensated \$50 for their time and were provided with a gift card to cover travel and participation expenses. The transcribed interviews were entered into NVivo data analysis software (QSR International Pty Ltd. 2015).

Data Analysis

Qualitative content analysis was used for analysis of the data. Use of Qualitative content analysis has been advocated for in qualitative descriptive studies (Milne and Oberele 2005, 413–420; Sandelowski 2000, 334–340; Sullivan-Bolyai, Bova, and Harper 2005, 127–133), because it allows for themes to surface directly and inductively from the data (Milne and Oberele 2005, 413–420). The process involved for qualitative content analysis included: (a) all authors immersing themselves in the data by listening to and reading transcripts many times so that data can be understood holistically; (b) the first author completed an initial line-by-line coding of the data which was then reviewed and checked by a second author to ensure the coding was consistent; (c) the authors identified 430 preliminary *meaning units*, which were then sorted into large themes with smaller and more specific categories within each; (d) co-authors then analyzed, discussed, and confirmed these groupings and investigated whether there were distinct differences in the findings based on the type of cancer reported. No differences were identified; (e) authors used emergent categories to organize codes into meaningful groups, providing a definition of each cluster; and (f) participants were presented with these themes with their respective quotes for member checking, which involved providing a summary of themes to participants with supporting quotes for each theme. Authors attempted to contact all participants to engage in these member checks, reaching out to participants up to three times. More than half of the participants ($n=23$, 53.5%) engaged in the process; however, almost half ($n=21$, 46.5%) of these participants had disconnected phones, and were not reachable. Of the reachable participants, almost all engaged in member checks. Following these member checks, no changes or amendments to the findings were asked for by participants.

Strategies for Rigor

We followed Milne and Oberele's (2005) strategies for rigor for qualitative descriptive studies (Milne and Oberele 2005, 413–420). These strategies ensured (a) *authenticity* to the purpose of the research; (b) *credibility*, or honesty and dependability of results; and (c) *criticality*, or intentionally making decisions throughout the research processes (Milne and Oberele 2005, 413–420). We utilized these strategies throughout the study by using a flexible and semi-structured interview script (which helped participants feel able to speak freely), ensuring participants' voices were correctly understood through probing for clarity when a statement was unclear, making sure that researcher interpretations were accurate by facilitating member checks, and finally by ensuring that data came inductively from the findings, through conventional content analysis. Authenticity and study integrity was further promoted in debriefing sessions conducted by the study co-authors where bias and thoughts about the findings were discussed (Milne and Oberele 2005, 413–420).

Results

Regarding depressive symptoms since receiving a cancer diagnosis, 26 (62%) participants indicated they had such feelings. Participants had a variety of perceptions of conventional mental health treatment. The focus now turns to these perceptions, followed by participant experiences with formal, informal (family and tribally-based) forms of mental health assistance and healing traditions, and finally, barriers to mental health help-seeking.

Ambiguous Perceptions of Conventional Mental Health Treatment

Some participants ($n=13$) described their mixed perceptions of the mental health service system. Generally, participants viewed families and informal support systems as primary forms of assistance, whereas conventional services were reported as a supplementary or “as needed” form of support, particularly when the informal support system may be lacking. Participant 15 wasn't interested in seeking mental health services because, “Right away I think they'll say, ‘Well here. Have some pills.’ And I think if you have people to talk to, you can deal with it.” When asked whether she thought such services would help, Participant 27 indicated, “No. Mental health. I don't.” When asked the same question, Participant 26 replied, “I don't think so. They asked me to go on something, or talk to someone, but I told them, ‘No, I've got my sisters and my mom to talk to if I feel bad.’” Similarly, when asked whether she'd consider using mental health treatment, Participant 8 indicated, “No. I never thought of it.” When asked whether she would be interested in conventional mental health service, she stated, “No I don't think I do.” Participant 39 reported:

Maybe, but I'm not sure. I mean it just like I said when I went to treatment I was taught how to, you know, take care of it. When I was talking about it, praying, crying, walking. So then mental health [treatment], I don't know if it would have helped me.

When asked whether counseling may have helped her cope with depressive symptoms, Participant 1 agreed with the sentiments of these other participants, stating, “Counseling? I doubt it.” Participant 42, in contrast, reported:

I've never sought help for depression before, but I think mental health services could help. I think maybe just to talk to someone about being worried that was my most thing is being worried and anxious over the future, mostly of what's going to happen and how to take care of things ... I really need to make a will which I don't have. And I work with the life insurance for the employees. I encourage all of them to make a will and then I didn't even have one. So, yeah, I think mental health services would help.

Likewise, Participant 22 indicated, "If a person should be able to talk to a counselor about anything, say anything, and, uh, uh, prescribe medications can help, I think. And, uh, so, uh, I think counseling and medications can help a person."

Mental Health Help-seeking Experiences Related to Depressive Symptoms

Conventional Mental Health Help-Seeking Experiences—Participants sought out a variety of forms of mental health care and conventional mental health services, including psychotropic medications and psychotherapy, as well as other forms of support, including seeking help from family and AI-specific healing methods (e.g., sweat lodges, healing ceremonies). Participants who sought formal help for mental health services primarily received care related to psychotropic medication and psychotherapy.

Psychotropic medication.: Participant 4 engaged in very short-term mental health treatment, primarily in the form of antidepressants:

Towards the end of my treatment here ... I really got depressed, and I was suicidal even thinking that [*sic*] 'what-ifs'. So [name of person] referred me, he got here he referred me. I got Zoloft I think as an antidepressant for about a month.

Despite only being on it for a month, she thought it was helpful. Participant 17 described the help she received in the form of antidepressants:

At first, I didn't know I was depressed until I started crying and couldn't stop. Anything made me cry. Happy, sad – made me cry. I was telling the doctor about it. I just cry all the time at anything. Then he put me on these antidepressant pills, which have helped a lot.

Psychotherapy.: Other participants engaged in psychotherapy. Participant 33 had a positive experience with counseling and stated:

I had depression and anxiety and panic. Anxiety attacks. So I had to have a counselor. I asked for a counselor to help me.

When asked whether she takes medication for her panic attacks, Participant 33 replied:

I used to ... when I first got it, I thought I was having a heart attack. It was so bad. So the doctors prescribed some pills for me. I took 'em like twice.

This participant seemed to prefer counseling over medication, as she went on to add, "If it's too bad [mental health symptoms], I'll just wait until I talk to my counselor. He gives me ways like relaxing exercises and things." She found this helpful, as stated, "Because there's someone to talk to. There's someone who's trained to help you, at least listen. They have

better understanding and better perspective of trying to help you.” Participant 32 also saw a counselor, which was helpful, as she described, “Just talk. Talk to you about your health, and taking care of yourself.” Others did not find conventional mental health services helpful. Participant 36 sought mental health services, but reported it not being useful, stating:

I actually went and talked to somebody too. Like I had a therapist there for a while, but it really didn’t help to tell somebody else my problems. It was kind of more sit there, and think about it, and think of how I was going to fix it on my own. It really didn’t.

Participant 10 received psychotropic medication and reported it as an unsatisfactory experience, describing:

They gave me medication for depression but I didn’t like that. It numbed my brain, and I had a headache, and I didn’t feel good so I quit taking those pills, and I said I don’t need pills just to feel better. I could make myself feel better. So that’s what I did. I made myself feel better.

Other forms of Mental Health Assistance: Help from Family and AI Healing Traditions

Other participants described seeking help through informal means. Many participants described conventional services as a ‘back-up’ for people who lacked an informal support system. As Participant 7 stated, formal mental health services may be particularly valuable, especially when informal support, such as family and social support, is not readily available:

The only reason why I didn’t have it [seek conventional services] was because I was surrounded by family and friends, I had so much. But if you don’t have that support from your family or you don’t have maybe even living family really, or-or you don’t have the friends that I did, or whatever the case may be. But absolutely, I encourage everybody to talk and to get help, because it is a life changing experience.

Participant 37 had a similar view, “I think it would be good for a people that don’t have a tight family like that. That would have someone to go to talk to you know.”

Participant 34 engaged in a sweat lodge¹ for her depressive symptoms, described as:

By going to a sweat. My husband would call where we Sundance at and ask them if we could use the sweat lodge down there. Our chief would say, “Yeah go ahead.” You have to do your own rocks and whatever. So he’d heat up the rocks and fire it up, and we’d go to sweat. And my kids. We’ll all go do it together. Some of my nephews out there would come and we’ll all go do a family sweat. I believe in my Lakota way of life ... because if it wasn’t for that, I probably would have gone into a depression because ... of like losing my mom to cancer and then of me having it. I almost went into a depression to where I told my husband, “I need to go to something. I need to go to sweat. Let’s go have a family sweat.” Because I felt the depression. I felt like I was pulling away from my husband, or he was pulling away

¹A sweat lodge is a hut or cavern heated by steam from water poured on hot stones used for purification and cleansing.

from me because of it. We didn't know how to cope with each other. We didn't know how to talk with each other.

Women described benefiting from and seeking out these non-conventional forms of mental-health support from both family and their community, and from AI healing ceremonies.

Barriers to Seeking Mental Health Services: Stigma and Confidentiality Concerns

Stigma and other barriers related to conventional services for depressive symptoms were described by 12 (29%) participants. One concern was confidentiality because in many tight-knit communities everyone knows everyone. Participant 4 had not thought of seeking mental health treatment because of confidentiality concerns with the Indian Health Service (IHS), stating, "No I didn't. Where I come from –mental health in my opinion, IHS? No. I don't think there's much confidentiality because [IHS] knows everybody down there you know." Similarly, participant 34 stated:

Yes, it would. But like I said we cannot trust the IHS here because people blab things. Even the mental health I mean I had bad experiences with our mental health here. I would not trust them. ... By the time it gets back to you it's a story that, 'oh yeah I tried to commit [suicide] last night,' ...they tell IHS.

Although Participant 35 did seek mental health treatment and found it to be helpful, she thought stigma was a big barrier, as stated, "Yeah there is [mental health services] if they want it. A lot of them [cancer survivors] are in denial. They think depression or seeking help is a bad thing. They don't see it as a good thing to see that, you know, how people seek help." Despite mental health treatment being thought to be effective, Participant 21 indicated the stigma was too great for the majority of people in the community to utilize it, stating:

Anybody that goes to mental health, they're gonna say 'they're crazy.' They'll say, "They're crazy." And nobody wants to be crazy, whatever that is. You know... [laughter] But, um, I guess, you know, your spiritually, and your physical, and your mental, those three things. Those things have to be in balance. You have to take care of those things. And if you don't, you'll have some problems.

As this participant described, a holistic look of well-being that includes spiritual, physical, and mental health is warranted.

Discussion

AI women reported seeking mental health support from a variety of non-conventional sources. The FHORT (Burnette and Figley 2017, 37–44) aids in interpreting and understanding the mental health experiences of AI women with cancer since many of the barriers (e.g. stigma) reported are congruent with the oppressive factors outlined in this framework. The importance of community and family in addressing mental health problems is also congruent with this framework's focus on resilience and transcendence despite adversity. Extant research has indicated that AIs were more likely to report negative experiences with mental health services compared to non-AI populations (Roh et al. 2014, 1–22). Importantly, over half (62%) of participants reported some depressive symptoms. First, almost a third (30%) of participants shared mixed perceptions of conventional mental

health services. The majority of these participants preferred to seek informal supports, through family and community support, and viewed conventional services only as an option if these informal supports were lacking. Some participants thought practitioners may be too quick to prescribe psychotropic medication, whereas others thought counseling and medication could be helpful. Notably, there was a lack of unanimous support or preference for conventional mental health services to treat depressive symptoms. This ambiguity regarding conventional services has been supported in extant research (Gone and Trimble 2012, 131–160; Buchwald, Beals, and Manson 2000, 1191–1199).

Second, the theme of mixed perceptions carried over to women's actual experiences with conventional mental health services for depressive symptoms. A few women had taken psychotropic medication for their depressive symptoms, but this seemed very time limited, with one participant taking them "for a month" and another participant taking anti-anxiety medicine "twice." Most participants who reported receiving psychotherapy reported finding it helpful to talk to someone who understands depression and anxiety; although one participant described counseling as not being helpful.

Third, many participants described seeking out informal support systems to cope with depressive feelings, which predominantly took the form of family. AI healing services, such as sweat lodges, were described as an important way to cope with depressive feelings, with a family sweat lodge being used to bring the family together and repair any damage or misunderstanding that the stress of the cancer experience had caused in family relationships. Finally, close to a third (29%) of participants described barriers to seeking conventional mental health services, which included concerns about confidentiality in tight-knit communities and stigma against using mental health services. Concerns about confidentiality have also been noted in other research on the use of conventional services for AI women, such as those who have experienced violence (Burnette 2015b, 1526–1545). Similarly, other research has identified stigma as a main barrier to mental health help-seeking among AIs (Roh et al. 2014, 1–22).

Implications and Conclusions

These results highlight several important questions for researchers and practitioners providing physical and mental healthcare for AIs. Although the perception of the general population may be that cancer survivors who experience depressive symptoms should seek conventional mental health services, the findings of this study suggest that AI women cancer survivors prefer and frequently utilize help from unconventional services, with formal care being supplementary if informal supports are lacking. Health practitioners may need to assess each individual client's perceptions and preferences of appropriate avenues to receive mental health services; if unconventional services are desired, practitioners can support ways to enhance, promote, and bolster such unconventional services. For instance, given the disproportionate rates of poverty and resource deprivation experienced by AIs (Gone and Trimble 2012, 131–160), families may need financial support, transportation, home health care, or other resources to be able to provide adequate support to cancer survivors. Health practitioners may need to develop partnerships with community members who may be able to provide AI healing practices, if AI cancer survivors seek such referrals. Given the very

mixed perceptions and experiences with conventional mental health services, individualized referrals and services should be offered that span formal and informal (family and AI traditional healing practices) options to choose from.

Moreover, results indicate that there is much room to enhance cultural sensitivity of mental health services for AI cancer survivors with depressive symptoms. This is important for providers to address because AIs are less likely to seek help when services reflect a lack of cultural sensitivity and competence among service providers (Griner and Smith 2006, 531). Extant research indicates a severe lack of culturally-based or culturally appropriate evidenced based programs for AIs (Gone and Trimble 2012, 131–160). Gone and Trimble (2012) add that social disadvantage tends to disproportionately affect AI groups, and research has found that poverty, higher levels of childhood trauma, and more negative experiences with mental health services act as disincentives for AIs mental health service utilization (Roh et al. 2014, 1–22). Concerns related to stigma and confidentiality must be addressed to directly restore and improve community perception and trust of mental health services. Community outreach, education, and evaluation of conventional services may be needed to address such concerns in a meaningful way.

Research on the health practices of AIs has generally found a preference for a mixture of both traditional AI and non-traditional (conventional mental health services) methods (Gone and Trimble 2012, 131–160; Buchwald, Beals, and Manson 2000, 1191–1199). Individuals with stronger cultural and tribal identification are more likely to desire treatment which incorporates traditional practices into it (Buchwald et al. 2000, 562–564; Canales 2004b, 18–44; Canales 2004a, 411–435). However, despite this preference, it is unclear how much use of both of these sources is facilitated by the current medical system for female cancer patients with depression (Buchwald et al. 2000, 562–564; Burhansstipanov et al. 2001, 424–433).

Practitioners' knowledge of AI patients' family histories, an understanding of holistic notions of health, and the importance of including traditional AI treatments is needed (Canales 2004b, 18–44; Canales et al. 2011, 894–911; Canales 2004a, 411–435). One possible way to blend conventional treatment with non-conventional forms of support can be seen in the example cancer programs that use a "Native sister model" where an AI women is matched with a "sister" who provides emotional and instrumental support throughout the process of screening and treatment for cancer (Burhansstipanov 1998, 2247–2250). There is also promising research in the use of talking circles for treatment of mental health problems of AI cancer patients, and this may be an area where treatment for co-morbid depression could be further developed (Becker, Affonso, and Beard 2006, 27–36).

Given research demonstrating that AIs are often open to both traditional and conventional mental health treatment approaches (Buchwald et al. 2000, 562–564; Canales 2004b, 18–44; Canales 2004a, 411–435), developing culturally sensitive mental health services that incorporate culturally relevant components is critical to promote healthier lives among AIs. The development of culturally-based and culturally-congruent evidenced-based programs for AI cancer survivors who experience depressive symptoms is highly needed. This development should occur in close collaboration with AI communities themselves to ensure

the cultural appropriateness of interventions and should include community input through community-based participatory research and community engaged research approaches (Burnette et al. 2017; Whitbeck 2006, 183–192).

Future Research and Limitations

This research uses self-report and only includes AI women from the Northern Plains region of the United States. Future research examining whether AI perceptions of mental health services—particularly regarding psychotropic medication, psychotherapy, and informal support systems—among non-AIs, and AIs across distinct regions, is warranted to deepen the understanding of potentially culturally specific approaches to health. More research on informal and tribally-based assistance is needed, more generally, given their ubiquitous use, and the lack of understanding of their effectiveness. Moreover, more research on potential barriers to tribally-based healing services is also needed, as factors related to cost, access, and other barriers are additional considerations. The unique stressors experienced by AI women make an analysis of the help-seeking resources they use especially important, especially one which uses a resiliency and strengths-based perspective and that highlights protective factors (Burhansstipanov et al. 2001, 424–433; Walters and Simoni 2002, 524–524).

Several limitations of the present study should be recognized. This qualitative study is not generalizable beyond its setting. Most participants had health insurance coverage, and, therefore, may differ from participants who do not have such insurance. Although no differences were found across participants with distinct types of cancer, future research should further explore whether type of cancer affects mental health help-seeking. Finally, distinctions need to be examined across AI/AN contexts, since mental health help-seeking experiences and practice may vary considerably by tribes, individuals, and regions.

In closing, participants stated that mental health support primarily came from family and tribally-based entities, with conventional mental health care being more salient when informal supports were lacking. The mixed perceptions espoused by participants may be related to a broader context of historical oppression. The utility of outside support, in the forms of family and social support and tribally-based services may be protective factors that have buffered against inadequate conventional health services. Health practitioners may need to assess patient's perceptions of appropriate avenues to receive mental health support services and work in a culturally congruent way with AI patients, which may include the incorporation of family and tribally-based support systems.

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Table 1*Sociodemographic Characteristics of the Sample (N = 43)*

Variables		N or Average	%
Age, <i>M</i> (<i>SD</i>)	Range: 32 to 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 \$1,499	21	(48.8)
	\$1,500–\$2,999	14	(32.6)
	More than \$3,000	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)

Table 2.**Semi-Structured Qualitative Interview Guide**

Q1. What is your typical day like?   Q2. How has your cancer diagnosis impacted your outlook on life?   Q3. Have you had feelings of depression since your cancer diagnosis and treatment? In your opinion, what made you feel this way?   Q4. Have you ever sought help for depression? Do you think providing mental health services would help? Why or why not?   Q5. When you felt depressed, how did you cope with the feeling? Did your religion, spirituality, or beliefs, and support you received help with this depression? What was most effective and helpful to you?   Q6. Has your family been supportive? Tell me about people who provide care with your illness? What support did or do they provide?   Q7. Do you have support systems outside of your family? What types of support have you received from them?   Q8. Do you feel supported by the American Indian community? What type of support did they provide?   Q9. In your opinion as an American Indian woman, what would make life better among American Indian cancer survivors?