**Executive Summary**

**Determinants of Care & Life Quality in American Indian Women with Cancer**

**Background of the Study**

Despite the fact that the population in the United States is now more diverse than ever, racial/ethnic minorities continue to be underrepresented among those receiving health services and among those included in health research. This underrepresentation is particularly striking in the cancer research arena. For years, studies have reported cancer health disparities, with racial/ethnic minorities showing higher levels of cancer incidence and mortality but lower rates of use of health services compared to whites.

American Indian (AI) women’s health issues have reached crisis levels, raising a nationwide call to arms to improve the quality of cancer care and health outcomes. Research has reliably demonstrated that both community-based participatory research and culturally appropriate cancer care can reduce disparities among cancer patients. These methods result in improved treatment compliance and recovery, better communication and social support for patients, lower re-hospitalization rates, and improved family satisfaction with patient care.

Geographic isolation and membership in a non-majority cultural group further compound the effect of cancer on the health and well-being of AI women, accentuating racial and ethnic disparities in cancer prevention and treatment outcomes. A key point is that little is generally known about the potential social determinants of the quality of cancer care and the quality of life among American Indian women. More specifically, there is no known research specifically addressing how South Dakota AI women perceive cancer in terms of health and cultural issues, despite the fact that this group is the fastest growing population in South Dakota. This study addressed the aforementioned gap in the literature by focusing on adult female AI cancer survivors residing in South Dakota.

**Methods**

We developed a Community Advisory Board (CAB) of key community and academic stakeholders for the purpose of developing culturally sensitive research/field procedures and surveys. Over the course of 12 months, our CAB meetings resulted in what the advisory board deemed a ‘culturally-sensitive’ research/field methodology. A mixed methodological community-based participatory research approach was implemented to investigate potential social determinants of the quality of cancer care and the quality of life among American Indian women with cancer residing in South Dakota. American Indian women aged 18 or older diagnosed with cancer in the past 10 years were recruited for the study from our partners and host hospitals: Rapid City Regional Hospital Cancer Institute in Rapid City, SD, and Avera Cancer Institute, Sioux Falls, SD. Percentages, means, standard deviations, and scale reliabilities are reported to provide preliminary baseline data.

**Results**

Seventy female American Indians were participated in the study (n = 70). A majority of the participants were born on a reservation (n = 54; 77%) and were enrolled members of the Dakota/Nakota/Lakota Tribe (n = 63; 90%). 93% (n = 65) reported attending a Native dance, pow wow, and/or a tribal ceremony. Most participants reported they had been previously treated by a traditional native healer (63%; n = 44) and that they use traditional Native remedies and/or practices to remain healthy and/or prevent illness (65%; n = 39). 94% indicated religious and spiritual affiliation. American English language was the primary language spoken at home (n = 42; 60%); over a third of the participants reported they spoke both English and American Indian language (n = 28; 40%).

On average participants were 56.30 years of age (SD = 11.38; range 32-77) with a body mass index (BMI) weight status category of obese (*M* = 30.51; SD = 6.00). Participant’s rated their overall health as poor (14%), fair (24%), good (54%), or excellent (7%) and their overall mental health as rated as poor (1%), fair (16%), good (57%), or excellent (26%). The most common cancers among participants were breast cancer (n = 23; 33%), cervical cancer (n = 20; 29%), colon cancer (n = 9; 13%), lung cancer (n = 4; 6%), non-Hodgkin’s lymphoma (n = 4; 6%), Sarcoma (n = 3, 4%), and others (n = 12; 17%). Approximately half of the sample (n = 31; 44%) reported a monthly household income of $1,000-$1,499 per month. Two-thirds of the participants had a post high school education or higher (n = 47) and were either married (n = 20; 29%) or divorced (n = 27; 39%).

Means, standard deviations, and reliability estimates on validated scales are as follows : religious/spiritual coping (*M* = 33.24; SD = 6.10; α = .74), spiritual well-being (*M* = 38.33; SD = 7.59; α = .85), meaning of illness (*M* = 16.45; SD = 4.70; α = .79), perceived social support (*M* = 37.07; SD = 13.48 α = .77), PHQ-9 depression (*M* = 6.83; SD = 6.07; α = .88), quality of life (M = 54.39; SD = 9.85; α = .92), and adverse childhood experiences (*M* = 2.54; SD = 2.34; α = .76).

**Findings**

Breast cancer, cervical cancer, and colon cancers were the most commonly reported cancers among female American Indian’s residing in South Dakota, accounting for 75% of all cancer diagnoses. Though female American Indian’s residing in South Dakota perceive their health and mental health to be mainly ‘good’ or ‘excellent’, participants on average were obese and data revealed levels of PHQ-9 depression score were >5, reflecting a clinically significant level of psychological distress and an increased likelihood of depression. Meaning of illness scale indicates moderately positive sense of their cancer. Quality of life score indicates moderate quality of life. According to the Medical Outcomes Study Social Support Survey instrument, our sample reported slightly high levels of support for the overall scale. Regarding adverse childhood experiences, the mean score was 2.5, which means that on average, respondents had been exposed to between two and three adverse childhood experiences.

Findings suggest our approach to better understand how South Dakota AI women perceive cancer in terms of health and cultural issues was successful and that the quality of life and social support are relatively high. Specifically, we found that

* our Community Advisory Board (CAB) appears to be an effective approach at building trust among American Indian’s in South Dakota
* our Community Advisory Board (CAB) successfully developed a ‘culturally sensitive’ research methodology
* levels of religious/spiritual coping were slightly high
* levels of spiritual well-being were moderate
* meaning of illness was moderately positive sense of the cancer
* levels of perceived social support were slightly high
* depression was a clinically significant level of psychological distress
* quality of life were moderate level
* adverse childhood experiences were exposed to between two and three adverse childhood experiences
* and obesity was high

These results have considerable research and, arguably more important, ‘real world’ implications. Future research should extend and translate these findings in to specific interventions and outreach programs aimed at reduce health and mental health disparities among AI women.