

PHYSICAL ACTIVITY AMONG NAVAJO CANCER SURVIVORS: A QUALITATIVE STUDY

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Abstract: Physical activity (PA) may improve quality of life and survival among cancer survivors; however, little is known about Navajo cancer survivor PA. We evaluated Navajo cancer survivor PA habits, barriers, and preferences through focus groups and interviews (n = 32). Transcripts were coded in NVivo and major themes summarized by consensus. Survivor exercise guidelines were largely unknown, but movement, resilience and life balance were valued. Most participants reported at ≥ 1 mode of current PA (n = 24; 71% walking, 46% work/homesteading). Barriers to PA included treatment side effects, limited access to programs, fear of “over doing it,” and family/friends encouraging rest. Preferences for PA varied.

INTRODUCTION

Physical activity (PA) has been associated with improved cancer-free survival (Schmitz et al., 2010; World Cancer Research Fund/ American Institute for Cancer Research, 2007), including 30-60% reduction in recurrence and mortality of colorectal and breast cancers (Irwin et al., 2011; Irwin et al., 2008; Meyerhardt et al., 2006), as well as reduced fatigue and improved quality of life, body composition, body image, and physical function among cancer survivors (Schmitz et al., 2010). Moderate amounts of PA have been demonstrated to achieve these protective benefits, such as walking 30 minutes per day at about 2.5 miles per hour (Irwin et al., 2011). Unfortunately, studies have not typically included large diverse populations, and none of the studies were specifically focused on American Indian and Alaska Native (AI/AN) cancer survivors.

Significant cancer disparities exist among AI/AN populations for several cancers. From 2001 to 2009, overall cancer mortality rates decreased nationally for White populations, but went up for AI/AN men and women (Centers for Disease Control and Prevention, 2016). AI/AN populations have the lowest 5-year survival rates of any group with 59.0% and were the only

group that did not see reductions in cancer mortality from 2001 to 2010 (Siegel, Ma, Zou, & Jemal, 2014). While the most common cancers among AI/AN populations are similar to national averages (lung, female breast, colorectal, and prostate cancer), death rates for certain cancers are more common among Native populations (gallbladder, stomach, liver, and kidney cancers) (White et al., 2014). Regional differences in incidence rates and outcomes across cancer types have been recognized, such that the most prevalent cancers and those with the highest mortality may differ among tribes (White et al., 2014).

The Navajo Nation has the second largest enrollment of any tribal nation (the largest being the Cherokee Nation), with a total enrollment of 332,129 according to the 2010 U.S. census, and 173,667 people living on the Navajo Nation reservation (U.S. Census Bureau, 2010). According to the most recent estimates from the Navajo Department of Epidemiology, cancer is the second leading cause of death among Navajo (behind only accidental injuries). With more than 500 deaths during 2006-2009, cancer accounted for approximately 12.7% of all deaths (Foley, Kinlacheeny, & Yazzie, 2016), with the most common cancers being breast, prostate, colorectal, and stomach cancer (Navajo Epidemiology Center, 2006).

Despite the size of the Navajo population and the aforementioned cancer disparities, research documenting the PA habits, barriers, and preferences of Navajo cancer survivors could not be identified in the literature. A better understanding of the factors related to PA is important to understanding the potential benefits of PA among Navajo cancer survivors. Further, cultural adaptation of successful evidence-based interventions may facilitate engagement and retention of participants in preventive interventions (Barrera, Berkel, & Castro, 2016).

Therefore, we conducted a qualitative study to assess current Navajo cancer survivor PA habits and potential barriers to engaging in adequate PA according to the American College of Sports Medicine (ACSM) guidelines for PA among cancer survivors (Schmitz et al., 2010). We also evaluated PA preferences in order to develop a tailored PA-based health promotion initiative in alignment with community beliefs and needs among Navajo cancer survivors.

METHODS

Study Population

Any adult Navajo with a history of cancer residing in the city of Flagstaff, AZ or in the selected rural Chapter on the Navajo Nation was eligible to participate in this study. Recent

research has found that Navajo often move between rural and urban locations on and off the Navajo Nation (Hardy et al., In review). Both rural and urban sites were selected to ensure representation from these different environments in order to plan a physical activity intervention serving rural and urban sites based on the qualitative findings. Participants were recruited through flyers, direct contact by the Navajo oncology nurse on the research team, and word of mouth. Study recruitment and data collection occurred between May 2015 and December 2015. The study was explained in both Navajo and English prior to consent, depending on preferred language. All participants provided consent prior to study participation. The protocol for human subjects research was reviewed and approved by the University of Arizona Institutional Review Board, the Northern Arizona Institutional Review Board and the Navajo Nation Human Research Review Board prior to study initiation.

Data Collection

Interviews and focus groups were used to identify PA habits, barriers to engaging in adequate PA (Schmitz et al., 2010), and PA preferences among Navajo survivors of various cancers. An experienced bilingual (Navajo and English) facilitator, who is also an oncology nurse, used a standardized discussion guide to lead each type of interaction. The interactions began with a traditional introduction in Navajo and an explanation of the study in Navajo and English. The traditional Navajo introduction includes sharing clan name, hometown, and family lineage (i.e., names of mother, father, grandmother, and grandfather on both sides of the family). Once consented, participants gave a brief cancer history and demographics as a part of continued introduction to one another.

The discussion guide incorporated the theoretical frameworks of the PEN-3 (Airhihenbuwa, 1995) and Health Belief (HBM) models (Rosenstock, 1974) to try and understand Navajo cancer survivor's beliefs and barriers regarding cancer and PA. The PEN-3 model includes the following domains: Cultural Identity (Person, Extended Family, Neighborhood); Relationship and Expectation (Perceptions, Enablers, and Nurturers); Cultural Empowerment (Positive, Existential, and Negative; Iwelunmor, Newsome, & Airhihenbuwa, 2014). Similarly, the HBM model considers individual perceptions, knowledge, attitudes, and beliefs and takes into account community influences and cultural appropriateness (Rosenstock, 1974).

Based on these models, the discussion guide included questions about: a) definitions of cancer, PA, and perceived cancer causes; b) current PA and barriers to PA; c) preferences for

delivery, type, and desired elements of existing PA programs, such as the ACSM Exercise Guidelines for Cancer Survivors (Schmitz et al., 2010); and d) ideas for program sustainability. The focus groups and interviews were intentionally semi-structured and open to allow participants to voluntarily raise important issues that may not have been raised by a more structured approach.

The focus groups took place in a conference room at either the Chapter House or the clinic (Arizona Oncology Associates, Flagstaff, Arizona). Participants sat in a circle for the discussion. Male and female focus groups were conducted separately to improve comfort with sharing details about cancer and cancer treatment-related issues, especially related to sex-specific cancers (e.g., prostate cancer and impotence; breast cancer and mastectomy, etc.). Interviews took place in a private room at the clinic or at the homes of individuals on the Navajo Nation to accommodate transportation issues.

Data Processing and Analysis

Audio recordings were used to document all focus groups and interview conversations, except for two participants where only field notes were taken based on participant preference. Recordings were translated from Navajo to English, as necessary, by a bilingual team member and reviewed by a second bilingual team member for concordance. All recordings were transcribed in full. Field notes were integrated into the data when recordings were not available.

A mixed deductive-inductive strategy was used to analyze transcripts. Data were first organized in NVivo by creating a framework of nodes based on the interview guide. These nodes served as a starting point and included broad categories based on the interview questions (i.e., cancer perceptions, barriers to activity, activity preferences, etc.). These nodes/categories were subsequently adjusted based on the data throughout the coding process. For example, categories were expanded upon (i.e., adding subcategories), or new categories were added that were not originally reflected in the broad framework. Coders were trained by the principal investigators. The first three transcripts were triple-coded independently by the coders (one Navajo; one Native, but not Navajo; and one non-Native coder). The coders iteratively read each transcript to identify reoccurring themes. Extensive discussions occurred regarding nodes/themes until team consensus was achieved for each node/theme. Since the coding between coders was concordant, only two coders were used for subsequent transcripts (one Navajo and one non-Native). After principal investigators approved the final coding, comparisons were made with the theoretical frameworks.

RESULTS

Participant Characteristics

We conducted 5 focus groups and 13 individual interviews among forty Navajo individuals ($n = 32$ survivors, $n = 8$ family/friends). Focus groups took place in both urban and rural settings. Interviews were primarily conducted in Flagstaff, AZ at the oncology clinic.

Both male ($n = 13$) and female ($n = 19$) cancer survivors participated in the focus groups and interviews (see Table 1), though focus groups were separated by gender. The mean age of the cancer survivors was 56.9 ± 12.3 years (males: 55.6 ± 13.0 years; females: 57.3 ± 11.8 years). The number of years since diagnosis was 4.7 ± 4.7 years (range $\leq 1 - 17$ years). Many participants used both Navajo and English during discussions, though two individuals used Navajo primarily. The majority of participants had experienced colon ($n = 10$; 31%) or breast cancer ($n = 10$; 31%). The other solid tumor types diagnosed among the Navajo cancer survivors were ovarian ($n = 2$), cervical ($n = 1$), esophageal ($n = 1$), gall bladder ($n = 2$), gastric ($n = 2$), prostate ($n = 1$), and kidney ($n = 1$). The hematologic cancers were acute myeloid leukemia ($n = 1$) and multiple myeloma ($n = 1$).

Self-Reported Physical Activity

Most of the survivors (75%) reported at least one mode of current PA (24 active; 1 inactive; 7 did not specify). The PA modes varied, but the majority of participants walked at the time of the focus group or interview (71% of survivors who specified activities). Of the participants that discussed frequency of activity ($n = 17$), 82% engaged in daily activity, while the remainder engaged in PA 2-4 days/week. The walking/running distance ranged from one block to 3 miles. Other activities included biking ($n = 2$; distance not specified), physical therapy ($n = 3$), stretching ($n = 1$), and homesteading ($n = 7$), which may include tending to livestock and/or crops, hauling water, and other chores. Several individuals reported more than one PA. Two individuals reported only work-related activity outside the home without specific daily duration.

Table 1
Characteristics of Navajo cancer survivors participating in focus groups and interviews (n = 32)

Characteristic	Mean or N	% ^f
Age, years	56.9	12.3
Sex		
Male	13	41%
Female	19	59%
Primary Language		
English	30	94%
Navajo	2	6%
Cancer Site		
Breast	10	31%
Colon	10	31%
Gynecologic, excl. breast ^a	3	9%
Gastrointestinal, excl. colon ^b	5	16%
Other ^c	4	13%
Time since diagnosis, years ^d	4.7	4.7
Current types of exercise ^e		
Walking or Running	17	75%
Biking	2	8%
Stretching	1	4%
Tending livestock and homestead related chores	7	29%
Physical Therapy	3	13%
Work related	4	17%
None	1	4%

^a Gynecologic, excluding breast cancer, represents ovarian (n = 2) and cervical cancers (n = 1); ^b gastrointestinal, excluding colon, represents esophageal (n = 1), gall bladder (n = 2), and gastric (n = 2); ^c prostate (n = 1), kidney (n = 1), hematologic cancers (n = 2); ^d based on year of diagnosis by self-report, not exact date; ^e some participants listed >1 type of activity, duration and frequency reported in less than half the sample. ^f Standard deviation rather than % for age; Missing data: Age: 3; Time since diagnosis: 7; Current types of exercise: 7.

Identified Themes

Four broad categories were identified in the remainder of the qualitative analysis: 1) perspectives of physical activity and cancer; 2) motivators for physical activity; 3) barriers to physical activity; and 4) preference for delivery, type, and desired elements of existing PA programs. Categories were followed by subthemes that exist within. The focus of the analysis and coding was on the emergent themes derived from the theoretically based discussion guide (see Table 2). Following coding, data were also organized according to the relationship and expectation domain of the PEN-3 and the HBM theoretical models to facilitate comparison with other articles in the literature (see Appendix A). This process follows similar procedures and is

grounded in similar theoretical underpinnings as other qualitative studies conducted in preparation for intervention development among cancer survivors (Scarinci, Bandura, Hidalgo, & Cherrington, 2012). This approach further allowed for developing practical summaries of barriers and facilitators of activity among the population and will be used to inform the development of the physical activity survivorship intervention. Below is a concise summary of the findings, with detailed findings in Appendix A.

Table 2
Emergent themes and select quotes from focus groups and interviews regarding physical activity among Navajo cancer survivors

Summary Statement by Theme	Representative Quotes
<i>Physical Activity and Cancer Perspectives</i>	
PA provides balance in life and is a necessity for tending the home and animals on the reservation. PA can be protective against cancer, but cancer diagnosis was not attributed to insufficient PA due to adequate PA prior to diagnosis.	<ul style="list-style-type: none"> • “That’s what our ancestors did, always move. You know move up until it gets dark and they go to sleep and next morning they do the same thing. They take the sheep out. It’s good exercise, you know. And it makes your mind think.” • “You can go to a weight room or else you can just go home and work, there is always plenty of work around your homestead, even though it may be hot outside just work with wiping the sweat away. Towards evening a person will be so tired it’s just like going to the gym. It’s the same.” • “I am just happy I got my health back. Yeah, that’s one thing I do not have to worry about, I go and enjoy bike ride; walking stuff like that” • “Where I grew up I use to be in sports, I grew up in sports. I took a lot of right food. When I got out of High School I was with the [mentions department where person was employed] for 14 years and we did a lot of physical I mean you have to be so I was with veteran for three years. Still I got it [cancer].”
<i>Barriers to Physical Activity</i>	
Cancer treatment side effects, lack of understanding how to safely get back to PA and how much PA to do, lack of personal and community resources, and social isolation were reported barriers to physical activity.	<ul style="list-style-type: none"> • “Well, cancer kind of like brings your body down. Like it just makes your body like um, less strong than you were before.” • “When I returned from treatment, I had no strength. I can’t even lift anything.” • “Me, my grandchild says lets go grandma you are not that weak, come on lets go, he loves to hike I am not at his pace he is only six I cannot go hiking on the big old mountain around our house you know, but like sadly there is a lot of limitation but I tried to do some yoga but it’s so hard your muscle is cramping, it’s just really hard if somebody could tell what my limits were maybe you know get me on a routine or schedule maybe then I can do it, because sometimes I overdo it.”
<i>Motivators for Physical Activity</i>	
Familial and social support, desire to support younger generations, self-motivation, restoring balance, honoring Navajo resilience, reducing burden to others, not showing weakness, Navajo traditions such as, rising before the sun to run or walk, were reported PA motivators.	<ul style="list-style-type: none"> • “Positive thinking, like he is saying, you have to think positively about yourself with prayers and tell yourself you can beat it.” • “I have a sister that I sometimes stay with in Flagstaff. As much as I don’t want to get off this couch, she’s like, ‘come on lets go even if you just walk a few steps or let’s go to town, let’s just go drive around you know and it makes a world of a difference so it does, there is an impact on you, you have to have that support.”

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Table 2 Continued
Emergent themes and select quotes from focus groups and interviews regarding physical activity among Navajo cancer survivors

Summary Statement by Theme	Representative Quotes
<i>Motivators for Physical Activity cont.</i>	<ul style="list-style-type: none"> • "It's got to be up to you, when I returned from treatment, I had no strength I can't even lift anything. Furthermore, 'I'm doing it for my kids' is what I thought to myself, and I started walking. Although I did not have the strength and courage, I did it. I have to get my strength back so I take my daughter with me, my youngest one, you have to take care of me and walk around with her." • "I have my daughter as my mentor who comes over. She tells me to 'do your exercise, mom.'" • "When I wake up the first thing in the morning at five o'clock and I ah that's when I ah that the day is young, the air is fresh, and I can concentrate on just running or walking down the road or the trail and I can see and hear the birds singing. I feel better just like your body is just ready, you are not heavy like ah in the middle of day or the end of the day when you go through the full day then you are tired. But when I get up in the morning I feel fresh."
<p><i>Preferences for Physical Activity</i></p> <p>Preferences for delivery and type of PA varied. Group-based PA preferences were supported by social support, peer accountability, and shared experiences with fellow cancer survivors. Perspective of cancer as contagious created a barrier to group programs for some. Individual-based PA program preferences were related to social discomfort and accessibility.</p> <p>Walking, hiking, and being outside most preferred. Tending to animals, land, and the home valued and necessary. Many traditional activities are PA and support cultural identity, emotional balance, and harmony with nature.</p> <p>Limited access to PA programs, infrequent and inconsistent programming makes consistent PA difficult. Sustainability, incentives, and trained lay or community staff that also participated in PA was desired.</p>	<ul style="list-style-type: none"> • "I like to be active with others that have the same disease that I have, maybe like some of them cancer survivor." • "I think for me it's just walking. A lot of it's just walking. You know, that's how we grow up too, starting with herding sheep." • "I don't, I don't see any cancer awareness or group therapy or anything like that. You know. I haven't been to a group at all." • "So maybe for people that don't have access to positive interaction with other people, there needs to be a group that goes around and says hey we're here! Come on, get on that bike let's go to the rodeo! Show some spirit!" • "You know I see people around which I'm so happy, they can ride horses, they can run. Just to keep them active you know, not being a couch potato." • "Just make sure your heart beat is really high for at least a good 15 to 30 minutes for your blood flow, that's what she [doctor] told me." • "Walking is what I prefer, aerobics too, [and] weightlifting. It depends on where you are at if you have the strength." • "They used to have a [Chapter name]. They used to have a physical uh therapy down there um with the machine in the community center. I don't know that happened. I haven't heard anything about it. There used to be a lot of people that used to go, but I never tried to go. I stopped by the chapter but I never asked about it."

Perspectives of Physical Activity and Cancer

While participants were aware that adequate amounts of PA and a balanced diet could serve as protective factors for cancer reoccurrence, many participants did not attribute their

cancer diagnosis to insufficient PA or the lack of a balanced diet. Prior to diagnosis many participants reported participating in adequate amounts of PA.

Motivators for Physical Activity

Social support from cancer survivor peers and/or family members was often cited as a facilitator for PA. A desire to be there for family played a central role in motivating survivors to engage in PA. Positive perspectives about PA were often centered on self-motivation, finding balance, and getting back to a place of harmony with oneself and one's surroundings. Being physically active was seen as a form of resilience and a tool for maintaining strength following illness. While some participants mentioned that they became less physically active post-diagnosis and during treatment, they perceived a return to their active lifestyles as a form of a physical and emotional resurgence post-treatment. Others were motivated by a feeling of pride and minimizing burden to others, electing to actively tend to their chores and maintain an active lifestyle so as not show weakness. However, though participants had these reasons for returning to activity and desire to do so, they were often limited by symptoms, not knowing what and how much to do safely or when it was okay to return to normal levels of activity. Navajo traditions, such as walking, running, dancing, and sheep herding, were proffered as a driving factor and motivator to increase PA as well. Survivors noted a desire to be able to share cultural traditions, such as rising before the sun to run or walk, especially with children or grandchildren.

Barriers to Physical Activity

Many participants cited diagnosis and treatment side effects as the primary deterrent to PA. Participants also indicated that PA is often not the highest priority when concerned about survival. Additionally, gaps in communication between health care providers resulted in conflicting information about treatment and PA, which then resulted in diminished PA. Cancer survivors reported being afraid of "over doing it" and that family members and friends often encouraged rest for recovery without adequate knowledge of balancing rest with activity. Those that had physically demanding vocations voiced concern over returning to work. Other concerns included knowing when to return, when to limit activity, and how to balance livelihood with symptoms. Finally, participants cited lack of access to dedicated PA programs and/or safe spaces for activity as barriers to structured PA. This limitation was due primarily to rurality.

Preferences for Delivery, Type, and Desired Elements of Existing PA Programs

Although preferences for individual- versus group-based PA programs were inconsistent, many participants cited the positive impact of social and familial support, peer accountability, and shared experiences with fellow survivors as justifications for group programs. However, the perception of cancer as contagious and spread either physically or spiritually prohibited contact with family and friends for some survivors. Preferences for individual-based programs were often rooted in feeling uncomfortable participating in PA with people who do not share similar limitations with cancer survivors. Some participants expressed preference for survivor-only group programs so that they could participate in PA in a safe space with their peers.

While community-based activities like Zumba were casually mentioned, walking, hiking, and being outside whenever possible were emphasized as culturally valued and preferred types of activities. Participants also expressed a preference for outdoor activities like tending to the homestead, including caring for animals, tending to land, chopping wood, and hauling water, and exclaimed the need for a resurgence of these activities, particularly among the youth. Traditional activities were seen as mutually beneficial considering that they could serve as PA while fostering cultural identity, emotional balance, and harmony with the surroundings.

While participants were aware of past and currently ongoing PA programs in the community, they noted that programs are often held in locations that hinder access to all interested community members and that programs are commonly a “one-day affair” that do not promote sustainability. Participants expressed that they have to find ways to motivate themselves because programs are sparse and often not held in spaces where they are most needed. Trainers and lay leaders that would participate in activity alongside the community members in training (i.e., walk the talk) were valued. Participants shared that when people feel personally invited they are more likely to attend activities because of the concept of shared accountability. Incentivizing with food or other gifts was mentioned as a viable approach to encourage survivors and their families to participate in PA programs.

DISCUSSION

This is the first study to evaluate the PA habits, barriers, and preferences of Navajo cancer survivors. The value of PA in the Navajo culture was evident, as was the value of resilience, which may serve as a natural motivator for PA among the Navajo during and following a serious illness (Teufel-Shone, Tippens, McCrary, Ehiri, & Sanderson, 2016). In

addition, while habits and preferences varied by individual, some of the variation appeared to be driven by current circumstances and the availability of resources. Participants were clearly willing to engage in PA given the appropriate guidance and resources.

Variation across individual survivors in terms of habits and preferences is common in other communities as well (Stevinson et al., 2009; Van Duyn et al., 2007). Differences in preferences may be effectively addressed by offering both individual support for PA, as well as opportunities and infrastructure to support group-based programs. Effective strategies to support a group-focused approach for obesity treatment and prevention among AI/AN communities have been previously summarized and are in keeping with many of the perspectives shared by Navajo cancer survivors herein: “1) build and reinforce social cohesion and collective efficacy, 2) use the motivating force of friendly competition, and 3) aspire to change local norms and policies by a) assuring high visibility of alternate behaviors, and b) engaging formal and informal leaders” (Teufel-Shone, 2006, p. 224).

Barriers to PA were consistent and included cancer- and cancer treatment-related symptoms, fatigue, lack of time, lack of guidance regarding cancer survivor PA parameters, fear of doing too much, and lack of access to PA programs and safe spaces. Researchers also identified fear of spreading cancer, either physically or spiritually via discussing it, as a barrier to group-based activity that would include family, friends, and others that had not had cancer.

Fortunately, the benefits of exercise in other cancer survivor communities to reduce symptoms, fatigue, and improve quality of life are clear, and exercise among cancer survivors is safe during and after treatment (Schmitz et al., 2010). The ACSM roundtable on exercise guidelines for cancer survivors (Schmitz et al., 2010) has clearly stated that cancer survivors should follow the 2008 Physical Activity Guidelines for Americans (Physical Activity Guidelines Advisory Committee, 2008). Avoidance of inactivity, even in cancer patients with existing diseases or undergoing difficult treatments, may also be advisable (Schmitz et al., 2010). These guidelines can be used in educational efforts promoting exercise as medicine. With respect to cancer as a contagion, the concept has been recognized in American Indian, as well as other communities (Collie & Kante, 2011; Dein, 2004) Continued education regarding the pathobiology of cancer may help to dispel the notion of cancer as a contagion (Collie & Kante, 2011; Dein, 2004) and can be included in cancer exercise PA programs and other community programs. Lastly, PA guidance for various types of cancer has been published, including frequency, intensity, and duration of activity; adaptations based on disease and treatment-related

adverse effects; and signs and symptoms indicating when to stop activity and seek medical care (Schmitz et al., 2010). The latter may be particularly important for those that have physically demanding jobs and are unsure when to return to work or reduce effort. This important information can be disseminated to clinicians, the community, and through targeted cancer survivor PA programs.

Importantly, other chronic disease prevention and management programs that include PA, such as the well-known Diabetes Prevention Program, are well accepted and have been successfully translated into diverse communities, including tribal communities (Hall, Lattie, McCalla, & Saab, 2016; Teufel-Shone, 2006), including for the Navajo Nation (program may be found at: <http://www.nnsdp.org/>). Therefore, it is reasonable to hypothesize that cancer survivor PA programs, informed by the HBM and PEN-3 guided research herein, can be similarly translated into the Navajo cancer survivor community and will be beneficial. Either creating specific cancer survivorship lifestyle programs or expanding the scope of practice of those leading diabetes prevention programs to cancer exercise is feasible as the main principles of exercise prescription and testing apply and training for specific clinical issues related to cancer can be easily added. Such an approach would enhance tribal capacity and has the potential to leverage resources, though funding challenges may need to be overcome if resources supporting diabetes prevention personnel are specific to diabetes grant sources. Nevertheless, whether in conjunction with or independent of diabetes prevention programs, effective tribal PA interventions for cancer survivors should include locally trained personnel, local leadership, stable funding, and culturally acceptable evaluation methods to assess health and social impact (Teufel-Shone, Fitzgerald, Teufel-Shone, & Gamber, 2009). The results presented herein, as well as the prior work in other chronic conditions, may be used to collaborate with the Navajo community to test the feasibility and effectiveness of a flexible, community-based PA intervention for Navajo cancer survivors that is both clinically and culturally appropriate.

This is the first qualitative inquiry of physical activity among Navajo cancer survivors. Consequently, the information presented will be valuable to PA and survivorship program planning efforts with the Navajo community. Successful recruitment of this sample indicates a community interest to dialogue about topics that are commonly regarded as taboo, suggesting a contemporary change in discourse about cancer in the community which could make interventions targeting cancer more feasible. This work also strengthens the relationships between the Navajo community and the health research community to collectively improve

efforts aimed at preventing cancer and increasing the quality of life among cancer survivors.

While relatively small in the context of the nation, the sample size of this study was quite large when considering that eligible participants needed to be of Navajo decent and have a past cancer diagnosis. The adequacy of the sample size was determined by data saturation; focus groups and interviews were added until there was a diminishing variation in the transcribed and subsequently coded data. Due to the nature of focus groups, not all participants shared information on each topic. More detail is needed regarding current PA behaviors, including consistent frequency, intensity, and duration. The location of the interviews and focus groups was designed to be convenient for participants, but did not necessarily correspond to residential location. Therefore, a brief demographic and PA questionnaire should be included in future studies. Self-selection into a focus group versus an interview was allowed to accommodate personal and cultural inclinations. While a potential limitation, the choice of interaction type with study staff enhanced recruitment as participants were given the liberty of selecting a format in which they would be most comfortable to share their cancer experiences, which could have potentially increased the richness of the dialogue.

CONCLUSION

This study took the first step in understanding PA among Navajo cancer survivors. Cancer PA programs can be tailored to the Navajo community by utilizing this information in conjunction with the evidence-based cancer exercise guidelines (Schmitz et al., 2010). Disseminating the ideas that exercise is indeed medicine, honors cultural tradition, and draws upon Navajo resilience may serve as important motivators for PA before, during, and after cancer treatment.

REFERENCES

- Airhihenbuwa, C. (1995). *Health and culture: Beyond the western paradigm*. Thousand Oaks, CA: Sage.
- Barrera, M., Jr., Berkel, C., & Castro, F. G. (2016). Directions for the advancement of culturally adapted preventive interventions: Local adaptations, engagement, and sustainability. *Prevention Science, 18*(6), 640-648. <http://dx.doi.org/10.1007/s11121-016-0705-9>

- Centers for Disease Control and Prevention. (2016). *Cancer among American Indians and Alaska Natives*. Retrieved from https://www.cdc.gov/cancer/healthdisparities/what_cdc_is_doing/aian.htm
- Collie, K., & Kante, A. (2011). Art groups for marginalized women with breast cancer. *Qualitative Health Research, 21*(5), 652-661. <http://dx.doi.org/10.1177/1049732310383989>
- Dein, S. (2004). Explanatory models of and attitudes towards cancer in different cultures. *Lancet Oncology, 5*(2), 119-124. [http://dx.doi.org/10.1016/S1470-2045\(04\)01386-5](http://dx.doi.org/10.1016/S1470-2045(04)01386-5)
- Foley, D, Kinlacheeny, JB , & Yazzie, D. (2016). *Navajo Nation mortality report, 2006-2009. Arizona & New Mexico data*. Window Rock, AZ: Navajo Epidemiology Center.
- Hall, D. L., Lattie, E. G., McCalla, J. R., & Saab, P. G. (2016). Translation of the diabetes prevention program to ethnic communities in the United States. *Journal of Immigrant and Minority Health, 18*(2), 479-489. <http://dx.doi.org/10.1007/s10903-015-0209-x>
- Hardy, Hulen, Saul, Hughes, Shaw, Pinn, . . . Begay. (In review). Locating wellness at home: Health and healthcare among American Indians in Arizona.
- Irwin, M. L., McTiernan, A., Manson, J. E., Thomson, C. A., Sternfeld, B., Stefanick, M. L., . . . Chlebowski, R. (2011). Physical activity and survival in postmenopausal women with breast cancer: Results from the women's health initiative. *Cancer Prevention Research, 4*(4), 522-529. <http://dx.doi.org/10.1158/1940-6207.CAPR-10-0295>
- Irwin, M. L., Smith, A. W., McTiernan, A., Ballard-Barbash, R., Cronin, K., Gilliland, F. D., . . . Bernstein, L. (2008). Influence of pre- and postdiagnosis physical activity on mortality in breast cancer survivors: The health, eating, activity, and lifestyle study. *Journal of Clinical Oncology, 26*(24), 3958-3964. <http://dx.doi.org/10.1200/JCO.2007.15.9822>
- Iwelunmor, J., Newsome, V., & Airhihenbuwa, C. O. (2014). Framing the impact of culture on health: A systematic review of the PEN-3 cultural model and its application in public health research and interventions. *Ethnicity and Health, 19*(1), 20-46. <http://dx.doi.org/10.1080/13557858.2013.857768>
- Meyerhardt, J. A., Heseltine, D., Niedzwiecki, D., Hollis, D., Saltz, L. B., Mayer, R. J., . . . Fuchs, C. S. (2006). Impact of physical activity on cancer recurrence and survival in patients with stage III colon cancer: Findings from CALGB 89803. *Journal of Clinical Oncology, 24*(22), 3535-3541. <http://dx.doi.org/10.1200/JCO.2006.06.0863>
- Navajo Epidemiology Center. (2006). *Cancer among the Navajo 1994-2004*. Retrieved from <http://www.nec.navajo-nsn.gov/Portals/0/Reports/Navajo%20Cancer%20Rpt%20062610.pdf>
- Physical Activities Guidelines Advisory Committee. (2008). *Physical activity guidelines advisory committee report*. Washington DC: U.S. Department of Health and Human Services. Retrieved from <https://health.gov/paguidelines/report/pdf/CommitteeReport.pdf>

- Rosenstock, I. M. (1974). Health Belief Model and preventive health behavior. *Health Education Monographs*, 2(4), 354-386. <http://dx.doi.org/10.1177/109019817400200405>
- Scarinci, I. C., Bandura, L., Hidalgo, B., & Cherrington, A. (2012). Development of a theory-based (PEN-3 and Health Belief Model), culturally relevant intervention on cervical cancer prevention among latina immigrants using intervention mapping. *Health Promotion Practice*, 13(1), 29-40. <http://dx.doi.org/10.1177/1524839910366416>
- Schmitz, K. H., Courneya, K. S., Matthews, C., Demark-Wahnefried, W., Galvao, D. A., Pinto, B. M., . . . American College of Sports, Medicine. (2010). American college of sports medicine roundtable on exercise guidelines for cancer survivors. *Medicine and Science in Sports and Exercise*, 42(7), 1409-1426. <http://dx.doi.org/10.1249/MSS.0b013e3181e0c112>
- Siegel, R., Ma, J., Zou, Z., & Jemal, A. (2014). Cancer statistics, 2014. *CA: A Cancer Journal for Clinicians*, 64(1), 9-29. <http://dx.doi.org/10.3322/caac.21208>
- Stevinson, C., Capstick, V., Schepansky, A., Tonkin, K., Vallance, J. K., Ladha, A. B., . . . Courneya, K. S. (2009). Physical activity preferences of ovarian cancer survivors. *Psycho-Oncology*, 18(4), 422-428. <http://dx.doi.org/10.1002/pon.1396>
- Teufel-Shone, N. I. (2006). Promising strategies for obesity prevention and treatment within American Indian communities. *Journal of Transcultural Nursing*, 17(3), 224-229. <http://dx.doi.org/10.1177/1043659606288378>
- Teufel-Shone, N. I., Fitzgerald, C., Teufel-Shone, L., & Gamber, M. (2009). Systematic review of physical activity interventions implemented with American Indian and Alaska Native populations in the United States and Canada. *American Journal of Health Promotion*, 23(6), S8-32. <http://dx.doi.org/10.4278/ajhp.07053151>
- Teufel-Shone, N. I., Tippens, J. A., McCrary, H. C., Ehiri, J. E., & Sanderson, P. R. (2016). Resilience in American Indian and Alaska Native public health: An underexplored framework. *American Journal of Health Promotion*. (E-pub ahead of print)1-8. <http://dx.doi.org/10.1177/0890117116664708>
- U.S. Census Bureau. (2010). *2010 census. American Indian and Alaska Native summary file. Dp-1 - profile of general population and housing characteristics: 2010*.
- Van Duyn, M. A., McCrae, T., Wingrove, B. K., Henderson, K. M., Boyd, J. K., Kagawa-Singer, M., . . . Maibach, E. W. (2007). Adapting evidence-based strategies to increase physical activity among African Americans, Hispanics, Hmong, and Native Hawaiians: A social marketing approach. *Preventing Chronic Disease*, 4(4), A102. Retrieved from https://www.cdc.gov/pcd/issues/2007/oct/07_0025.htm

White, M. C., Espey, D. K., Swan, J., Wiggins, C. L., Ehemann, C., & Kaur, J. S. (2014). Disparities in cancer mortality and incidence among American Indians and Alaska Natives in the United States. *American Journal of Public Health, 104*(Suppl 3), S377-387. <http://dx.doi.org/10.2105/AJPH.2013.301673>

World Cancer Research Fund/ American Institute for Cancer Research. (2007). *Food, nutrition, physical activity, and the prevention of cancer: A global perspective*. Washington DC: AICR. Retrieved from http://www.aicr.org/assets/docs/pdf/reports/Second_Expert_Report.pdf

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Appendix A
Qualitative findings organized according to the PEN-3 and HBM Models

PEN-3 Model	Qualitative Findings
<i>Perceptions of Physical Activity</i>	<p><i>Positive</i></p> <ul style="list-style-type: none"> • PA is an imperative part of a healthy lifestyle • PA is associated with self-motivation, seeking balance, and returning to a place of harmony with themselves and their surroundings • PA can facilitate cancer and other disease treatment adherence • PA is seen as a way to overcome disease and the accompanying symptoms • Many traditional daily activities like tending to animals, land, and family responsibilities allow people to participate in PA <p><i>Negative</i></p> <ul style="list-style-type: none"> • While participants were aware that a healthy lifestyle could serve as a protective factor for cancer reoccurrence, many participants did not attribute their cancer diagnosis to the lack of sufficient PA or a balanced diet. On the contrary, participants often mentioned that prior to diagnosis they were participating in adequate amounts of PA and that the diagnosis and treatment process (symptoms, fatigue, lack of time, etc.) has been the primary deterrent of PA • Participants are often afraid of “overdoing it” • Beliefs that they are unable to bounce back / return to prior level of function • PA recommendations for survivors (when to do what) largely unknown
<i>Physical Activity Enablers</i>	<p><i>Positive</i></p> <ul style="list-style-type: none"> • Participants are aware of past and current PA programs in both urban and rural settings • Incentivizing with food or other gifts was identified as viable approach to have people and their families participate • Perceived shared accountability created when people feel personally invited to PA programs and related activities increases likelihood of individual and family attendance • Adequate access to available fitness centers was cited as a motivator for structured PA • Trust in some community organizations (chapter house, school) • Participant’s lifestyles require them to complete significant amounts of physical activity (housework, tending to land/livestock) <p><i>Negative</i></p> <ul style="list-style-type: none"> • Limited financial means • Limited services available in close proximity (depending on location) • Logistic challenges during treatment (travel, housing during extended treatments, livestock/ agriculture responsibilities during treatment, etc.) • Lack of community programs for cancer survivors
<i>Physical Activity Nurturers</i>	<p><i>Positive</i></p> <ul style="list-style-type: none"> • Participants are often encouraged by their family and friends to participate in physical activity • The social support from cancer survivor peers and/or family members were often cited as facilitators to PA • Family plays a central role in motivating survivors to get up and moving • Seeking balance is seen as one of the primary motivators for PA • Being adequately informed about existing PA programs promotes attendance • Cultural alignment with aerobic PA (run towards the sun, running in ceremonies) • Environmental need for physical activity (farming, housework) • Cultural emphasis on restoring balance in life <p><i>Negative</i></p> <ul style="list-style-type: none"> • Cultural taboo on discussing cancer (even with family members) • Cultural gender roles can discourage females from participating in PA • Cultural prevalence of alcohol, drugs, and other unhealthy behaviors • Lack of others participating in regular, organized PA • Family members often unaware of PA recommendations for survivors and tell survivors to remain sedentary

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Appendix A Continued
Qualitative findings organized according to the PEN-3 and HBM Models

Health Belief Model	Qualitative Findings
<i>Perceived Susceptibility</i>	<ul style="list-style-type: none"> • While participants were aware that a healthy lifestyle could serve as a protective factor for cancer reoccurrence, many participants did not attribute their cancer diagnosis to the lack of sufficient PA or a balanced diet. On the contrary, participants often mentioned that prior to diagnosis they were participating in adequate amounts of PA and that the diagnosis and treatment process (symptoms, fatigue, lack of time, etc.) has been the primary deterrent of PA • Correct identification of behavioral lifestyle choices as a risk factor, i.e. diet and PA, for cancer • Incorrect identification of risk factors among family/community members (contagious) • Fatalism (risk factors beyond person's control) • Preventive care is a lower priority when concerned with survival
<i>Perceived Severity</i>	<ul style="list-style-type: none"> • There have been many changes in the Navajo community that have diminished the amount of PA that people get • Sentiments shared by older participants were PA in the community diminishes with each generation; participants cite the availability of processed foods and convenient food outlets with diminishing traditional food cultivation methods, which decreases quality of food consumed and PA
<i>Perceived Barriers</i>	<ul style="list-style-type: none"> • PA is often not a priority when cancer survivors are worried simply about survival • Inefficient communication between healthcare providers results in conflicting information about treatment and PA • Lack of access to dedicated PA programs and/or safe spaces for activity, due primarily to rurality, are common barriers • Patient-provider gaps in communication cause participant confusion about PA activity norms and expectations • Current PA programs are few and far between. They are often one-day events that participants perceive to be unsustainable • Current PA programs are commonly held in centralized/urbanized locations that maybe be difficult for the community in need to access; those that live in rural areas are particularly affected • While participants were aware of past and currently active PA programs, they claimed that programs are often held in locations that hinder access to all interested community members and that programs are commonly a "one-day affair" that do not promote sustainability. Participants express that they have to find ways to motivate themselves because programs are sparse and often not held in spaces where they need them • Treatment side effects (fatigue, muscle weakness, persistent pain)
<i>Perceived Benefits</i>	<ul style="list-style-type: none"> • Positive perspectives about physical activity are often centered around self-motivation, finding balance and getting back to a place of harmony with oneself and one's surroundings • There is a perceived need to participate in PA to overcome the disease and the implied symptoms • Being able to perform even the smallest amount of PA is seen as a way of staying motivated to adhere to treatment to try to get back to a place of balance • Having adequate access to available fitness centers was cited as a motivator for structured PA • Some participants exclaim that sufficient PA as part of a healthful lifestyle can prevent cancer reoccurrence • Understand benefits of physical activity and healthy, traditional diet • Emphasize personal responsibility and perseverance • Desire to be healthy and support family

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Appendix A Continued
Qualitative findings organized according to the PEN-3 and HBM Models

Health Belief Model	Qualitative Findings
<i>Self-Efficacy (HBM)</i>	<ul style="list-style-type: none">• There was a consensus that participants would be willing to participate in PA programs• Participants often expressed that they are self-motivated to participate in PA, even without the presence of a structure program• The participant's expressed need to find balance and harmony keeps them motivated to adhere to healthful behaviors• Sense of personal responsibility to get back to function• Participant's cancer diagnosis and treatment process is their first experience with physical limitations that are often discouraging of any PA• Fatalism• Lack of knowledge about appropriate PA during and after treatment• Persistent treatment side effects and other conditions not related to cancer (low back pain, diabetes, etc.)

HBM = Health Behavior Model; PA = physical activity