
ACTION-RESEARCH

Development of a Culturally Relevant Physical Activity Intervention for Navajo Cancer Survivors

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Despite well-documented benefits of physical activity for cancer survivors, few interventions have been developed for Native American cancer survivors, the population with the poorest survival rates of any group. This paper describes the development and cultural adaptation of a physical activity intervention for Navajo cancer survivors using Intervention Mapping (IM). IM procedures were guided by the PEN-3 (Perceptions-Enablers-Nurturers) and Health Belief Models and informed by a qualitative study with 40 Navajo cancer survivors and family members. For each theoretical construct (perceived benefits, barriers, enablers of healthy behaviors, etc.), a measurable objective was identified. These objectives were then matched with intervention strategies. The IM process indicated the need for a highly culturally sensitive environment (site and providers), culturally acceptable measurements and materials, and integrating cultural and environmental activity preferences. Program objectives aligned directly with these areas. Intervention strategies included: (a) collaboration with providers sensitive to historical/cultural context and environmental barriers; (b) cultural adaptation of surveys, non-invasive physical measurements, no biospecimen storage; (c) materials, terminology and symbols embracing cultural values of return to harmony; (d) physical activities that are flexible and aligned with cultural preferences and environment/travel issues (e.g., outdoor walking; community and home-based options; portable, inexpensive resistance equipment; local resources; family/friends participation and more community cancer education); (e) clinical adaptations by site and symptoms. This study is the first to document the process of adaptation of a physical activity program for Navajo cancer survivors. Objectives and strategies incorporated via IM are expected to foster sustainability and enhance uptake, satisfaction, and adherence.

Keywords: Intervention Mapping; Cancer Survivor; Native American; Navajo; Physical activity; Exercise

Introduction

Cancer is the second leading cause of death among the Navajo people, one of the largest Native American nations in the United States (U.S.) (Navajo Epidemiology Center [NEC], 2013). Breast, prostate, and colorectal cancer are the three most common types of cancer among the Navajo (NEC, 2018). Native Americans, including Navajo, are diagnosed with cancer at more advanced stages compared to non-Hispanic Whites (NEC, 2018; Siegel, Ma, Zou, & Jemal, 2014) and have the poorest five-year cancer survival rate of any group in the country (Clegg, Li, Hankey, Chu, & Edwards, 2002; Siegel et al., 2014). Although community-based resources and Native American cancer navigation trainings have been developed (Native American Cancer Research Corporation, n.d.), to date, the Navajo, like many other Native American tribes, have limited access to cancer-related resources (Bea et al., 2019).

Physical activity is an essential component of cancer prevention and control. Physical activity can aid in the reduction of cancer recurrence (Marmot et al., 2007; Meyerhardt et al., 2006; Schmitz et al., 2010). Physical activity also decreases fatigue and improves body composition, physical function, and overall quality of life among cancer survivors across multiple populations (Schmitz et al., 2010). However, despite substantial disparities in survivorship outcomes among Native Americans, evidence-based physical activity programs have not been developed for any tribal nation including the Navajo Nation (Bea et al., 2018). Notably, the Native American Cancer Research Corporation does have a Physical Activity and Cancer Branch, providing information about national activity guidelines for cancer survivors and culturally tailored vignettes on emotional and spiritual benefits of physical activity (Native American Cancer Research Corporation, n.d.).

A qualitative research study embedded in the Partnership for Native American Cancer Prevention (NACP) identified the need for increased physical activity and physical activity related education, programs, and resources for Navajo cancer survivors (Bea et al., 2018). A physical activity intervention, based on this research, was developed according to the cultural needs, beliefs, and norms of Navajo cancer survivors (Bartholomew, Parcel & Kok, 1998; Scarinci, Bandura, Hidalgo, & Cherrington, 2011). The purpose of this article is to describe the development of the theory-based, culturally relevant, physical activity intervention among Navajo cancer survivors using intervention mapping.

Methods

Intervention Mapping

Intervention mapping (IM) is a systematic approach to intervention development that incorporates both theoretical and cultural factors. It has previously been used to create effective, theory-based, culturally relevant, cancer prevention interventions (e.g., Scarinci et al., 2011). For this reason, IM was used as a model when designing a physical activity intervention for Navajo cancer survivors. Bartholomew, Parcel, and Kok (1998) expanded the IM framework to include a seven-step process to fully capture all relevant factors involved in the development of a theory-based, culturally relevant intervention for Navajo cancer survivors. The first five steps represent the processes set forward in planning the intervention. They include: (a) assessment of needs and cultural norms, (b) stakeholder identification, (c) objective and outcome identification, (d) development of theory-based research design, and (e) cultural adaptation of the intervention. The final two steps, implementation and assessment of efficacy, for the physical activity program described herein are currently ongoing.

Assessment of Needs, Cultural Norms, Beliefs, and Perceptions (Qualitative Study)

Interviews and focus groups provided a qualitative exploration of specific needs, beliefs, perceptions, and cultural norms common among Navajo cancer survivors. Two constructs, the PEN-3 and Health Belief Model (HBM) were chosen to guide this study. These models were chosen to provide a comprehensive view of cultural perceptions, enablers, and nurturers relating to physical activity and cancer, as well as key factors related to the creation of behavior change and positive action. The details of PEN-3 and HBM have been described throughout the literature relating to the development of culturally relevant interventions (Green & Murphy, 2014; Hiratsuka, Trinidad, Avey, & Robinson, 2016; Iwelunmor, Newsome, & Airhihenbuwa, 2014), including research on intervention development for cancer survivors (Scarinci et al., 2011).

The qualitative study included 40 Navajo cancer survivors ($n = 32$) and family members ($n = 8$) participating in five focus groups and 13 individual interviews conducted in both rural and urban settings. Participants were on average 56.9 years old (standard deviation = 12.3 years), and were approximately five years post diagnosis. About one-third of participants were colorectal cancer survivors and one-third breast cancer survivors. Participants either lived in a moderate-size urban community adjacent to the Navajo Nation or lived nearby in a small rural community (population of approximately 1,000 residents) about 45 miles from the urban area. Some cancer services are available in the urban community, but more complex procedures may require travel to a larger urban area over 125 miles away.

The focus groups took place at two local community organization offices. The individual interviews primarily took place in an office at the oncology clinic. The interviews were in English and Navajo and lasted between 16 minutes and 1 hour and 41 minutes. A wide variety of cancer types were represented, with a majority of survivors being colorectal and breast cancer survivors. Participants were asked about physical activity habits, barriers, and preferences. They were also asked about their perceptions of cancer causes, prevention, and treatment. All interviews and focus groups were transcribed by a bilingual person fluent in Navajo and English. To assess inter-rater reliability, the first 15% of all transcripts were triple-coded by a staff member, researcher, and graduate student. Any differences were resolved during in-person meetings. All coding ensured at least one Navajo speaker with in-depth cultural knowledge coded the transcripts. Themes

from the qualitative study were coded using NVivo qualitative data analysis Software (QSR International Pty Ltd. Version 10) and were summarized by the research team. The study was approved by all relevant stakeholders including the Navajo Nation Human Research Review Board (NNHRRB, NNR.14-192), which also continuously reviewed and approved presentations and manuscripts.

Key Themes

In brief, the qualitative analysis supported the need for a culturally relevant community physical activity program for Navajo cancer survivors. Key themes identified were related to knowledge, access, trust, and cultural relevance. There was limited knowledge about cancer, cancer prevention, and physical activity guidelines in survivorship among many survivors and community members. Participants identified a lack of community lifestyle programs for Navajo cancer survivors as well as a lack of Navajo (speaking) providers and treatment options close to home. They were uncertain about or had negative experiences with Western medicine, including a sense of cultural misalignment with the treatment environment. A full summary of methods and major themes from the qualitative phase, organized according to the PEN-3 and HBM constructs, may be found in Bea et al. (2018, 2019).

The qualitative analysis also demonstrated the need for the development of an intervention in an environment that is highly culturally sensitive and tailored to the needs of the population. Providers need to have a thorough understanding of the historical and cultural context, as well as the environmental facilitators and barriers of the survivors. This included ensuring that all educational materials and resources: (a) used culturally appropriate language, symbols, and images; (b) identified local resources; and (c) emphasized culturally appropriate activities and measurements (including a preference for not storing bio-specimen).

Stakeholder Identification and Community Engagement

To inform the IM process, engagement with community stakeholders took place over two years through several activities and culminated in the development and execution of the qualitative study among Navajo cancer survivors. Throughout this process, stakeholders offered recommendations for additional collaborators, study sites, tribal processes, and improvements of study components. In addition to the need for a lifestyle-focused intervention among Navajo cancer survivors, ongoing meetings revealed additional stakeholders that would need to be engaged to successfully implement a physical activity intervention with the Navajo. The stakeholder identification and community engagement process was initiated through collaboration with the “outreach” core of the umbrella center grant the project is embedded in. This center is a partnership between two academic institutions (a larger cancer center and a smaller institution located near the tribal nation) and has several cores including research, student training, and outreach. The outreach core directly interacts with tribal nations to support cancer programming and education. A brief timeline of the process is outlined below:

• Months 0–3:

- Faculty from both academic institutions met and formed the principal investigative team.
- The principal investigators reached out to the partnership's outreach core and Community Advisory Council (CAC) to seek advice and connections to people intimately familiar with cancer care, the Navajo culture, and the Navajo language. One connection was a Navajo oncology nurse experienced in qualitative data collection and direct patient care to Navajo people. She became part of the research team. The CAC further connected the team to relevant resources and policy.

• Months 3–6:

- The team hired several Navajo students to support the project.
- The team consulted with several Native American faculty at the academic institution to gain deeper insight into working with the Navajo Nation and tribal approval processes.
- Approval from a local organization serving Navajo cancer patients and survivors (the oncology clinic) was secured as a location for participant recruitment and focus group/interviews.

• Month 6–12:

- The team engaged with local communities through “chapters,” the smallest local Navajo government unit. There are 110 chapters in the Navajo Nation. Engagement consisted of meeting with local chapter leadership individually, planning and attending meetings, as well as presenting at the full board meetings where community members voted on project approval. Final approvals were demonstrated by a formal signed “resolution,” an agreement between the research team and the government entity outlining the scope, expectations, and requirements.

- **Months 12–15:**
 - Following local meetings, the team received approval from the regional agency council (one of five agencies on the Navajo Nation, which meets every three months).
 - The team applied for and received a permit from the Navajo Nation Historic Preservation Department. This was a requirement since we documented the oral histories of Navajo cancer survivor experiences through audio recording.
- **Months 15–18:**
 - The principal investigators attended Navajo Nation Human Research Review Board (NNHRRB) meetings and consulted with board members prior to presenting their study.
 - We received approval from the research board of both academic institutions.
- **Months 18–24:**
 - The research team presented the project to the NNHRRB and received feedback and approval. We further engaged several local Native American serving organizations to seek locations for implementation of the future intervention.

The process of trust-building was facilitated by: (a) frequent face-to-face meetings throughout the process, (b) engagement with a range of local and regional leaders, (c) building a research team with strong Navajo representation, (d) being respectful and patient with the administration of processes and addressing the concerns of each stakeholder group, and (e) developing a project with direct benefits for the Navajo people. Engagement with all stakeholders is ongoing and the comprehensive list and their roles are outlined in **Table 1**.

Objective and Outcome Identification

Several different objectives were identified for the physical activity (PA) intervention, the phase following the IM process. These included quantitative objectives to demonstrate: (a) efficacy of the PA intervention; (b) emotional, behavioral, and social effects of the intervention on participants; and (c) program feasibility and sustainability.

Quantitative objectives for the planned PA intervention (i.e., aerobic capacity, body composition, physical function, metabolic markers, etc.) were chosen based on their relevance to PA and previous associations with outcomes of quality of life, cancer recurrence, and mortality (Wolin, Schwartz, Matthews, Courneya, & Schmitz, 2012). Participant burden, related to planned measurements including cost, time, and invasiveness, was considered in balancing scientific rigor with sensitivity to population values and challenges. Objectives related to cancer survivors' sense of emotional, behavioral, and social wellbeing (e.g., low perceptions of health, low perceptions of PA level, and potential social isolation) emerged in qualitative themes from the focus groups and interviews.

Social isolation was not a theme that was explicitly expressed by participants. Instead, social isolation was inferred from participant discussions of cancer as a contagion, which limited interactions with family and friends for some survivors. The Patient Reported Outcome Measurement Information System (PROMIS) is a comprehensive set of person-centered measures developed by the NIH and validated in several cultures and populations (Bjorner et al., 2014; Cella et al., 2010). The PROMIS-10 and PROMIS social isolation subscale were selected for their relevance to identified needs, limited participant burden, and support of the NIH goal to enable comparison across studies (Bjorner et al., 2014; Cella et al., 2010). Additionally, the Leisure-Time Exercise Questionnaire was selected to evaluate reported amounts of PA (Amireault Godin, Lacombe, & Sabiton, 2015; Godin & Shephard, 1997).

Additional objectives, informed by the qualitative study, included increasing knowledge of PA and the role of PA in cancer prevention and cancer survivorship. Qualitative study participants identified these elements as areas of need in the community. A final objective was to create a sustainable community PA program that could remain in place after the completion of the research.

Development of Theory-Based Research Design and Intervention Methods

Specific intervention design and methods were developed using the PEN-3 and HBM as the theoretical foundation (Hiratsuka et al., 2016; Scarinci et al., 2012). **Table 2** lists proposed intervention activities according to the PEN-3 and HBM.

Target behaviors and intervention protocols lay on the foundation of the American College of Sports Medicine's (ACSM) PA recommendations for cancer survivors (Schmitz et al., 2010; Wolin et al., 2012). In addition to type, intensity, and duration of activities prescribed for survivor exercise in the ACSM guidelines, the intervention included educating participants and the community that most cancer survivors do not

Table 1: Stakeholders in the development of a physical activity (PA) intervention with the Navajo population.

Stakeholder Group	Role
<i>End-Users</i> • Cancer survivors • Survivor family members and friends	• Determine need/desire for PA program among Native cancer survivors • Describe barriers, facilitators, and preferences for PA intervention • Provide ideas for sustainability of the PA intervention • Identify gaps in community knowledge related to PA and cancer prevention • Participate in and evaluate culturally and clinically tailored cancer survivor PA intervention for Navajo cancer survivors
<i>Governance</i> • Institutional Review Boards: Navajo Nation Human Research Review Board • Navajo Nation Governmental Organizations: Health Department Agency Councils, Chapter Houses	• Support planning and implementation of qualitative study and PA intervention including review of protocol as well as providing space for participant consent, focus groups, and interviews • Affirm need and community support for program (vote and signed resolutions) • Oversee safety for research participants
<i>Influencers</i> • National Institute of Health (NIH) • Partnership for Native American Cancer Prevention (NACP) • Native Community Action Committee	• Provide funding mechanism, peer review, tracking, and financial support • Facilitate understanding of tribal processes, norms, and preferences • Provide introduction to other stakeholders • Champion program in community • Facilitate dissemination of outreach materials and research findings
<i>Providers</i> • Local healthcare facilities: Arizona Oncology Associates • Community health organizations focused on serving Native Americans locally: Indian Health Services, Tribally directed health facilities (638), Native Americans for Community Action • Native serving and/or Native owned fitness facilities • University faculty, students, and study staff	• Facilitate identification of survivors that may benefit from the program • Provide space for consent of participants • Provide space for PA intervention • Increase scope of practice through specific training in cancer exercise • Support initiation and implementation of the program • Provide coaching throughout intervention, including on-site and at-home (via phone, email, or text depending on participant preference) • Facilitate sustainability of the program

need medical clearance to be active and should be encouraged to become active after treatment. Cautions and adjustments for special clinical circumstances, such as immune compromise and lymphedema were addressed in the intervention plan (Hiratsuka et al., 2016; Scarinci et al., 2012).

A randomized delayed-start design was chosen to allow for a control comparison without withholding the intervention from any participants. This design provided a scientifically rigorous research study to assess effectiveness while also offering the intervention to all interested and eligible survivors. At baseline, participants would be measured and then randomized to delayed-start or immediate-start for the exercise intervention.

Adapting Theory-Based Methods to Fit Culture and Specific Needs

The next step in intervention development was to modify specific elements of the intervention to be more culturally relevant and appropriate, using the results from the qualitative analysis as a guide. These modifications are detailed in **Table 3** categorized by the dimensions of language, persons, metaphors, content, concepts, goals, methods, and context. Some key elements of the intervention are discussed below:

Modification of questionnaires to fit culture. For example, culturally irrelevant activities such as “squash,” “judo,” “alpine skiing,” and “golf” were removed from the Leisure Time Exercise Questionnaire. In addition to the relevant existing cues (e.g., walking or running), we also decided to cue participants for culturally specific activities such as “agricultural work” and “herding sheep” for

Table 2: IM of a PA intervention for Navajo cancer survivors.

Theoretical Construct	Intervention Objectives	Strategies for Activity or Group Sessions	Strategies for Individual Activities
Perceptions (PEN-3)	- Reinforce accurate beliefs about cancer causes, environmental, and behavioral factors - Reduce inaccurate beliefs about cancer - Tap into resilience in culture and emphasis on tribal kinship, family, and community support - Improve understanding of quantity and intensity of PA during and after cancer treatment	- Promote health, fitness, and balance with cultural beliefs - Health coaching to increase perceived control over health - Provide education about cancer in Navajo and English and disseminate widely across community and partner agencies - Facilitate recognition of strength in the community in general and with regard to treatment and health post-diagnosis	Personalize the education depending on individuals' beliefs and level of knowledge
Enablers (PEN-3)/ Perceived Barriers (HBM)	- Decrease structural barriers to seeking treatment where possible (financial, logistic, and cultural) - Support local organizations' capacity to provide services - Decrease fear about screening and finding out test results - Promote knowledge regarding the U.S. healthcare system (what services are available and where to access services) - Reinforce trust of community health representatives - Improve skills to promote communication with healthcare providers about cancer among all family members as well as community members	- Discuss healthy changes that are possible within structural and environmental limitations at the family and individual level - Disseminate information about screening recommendations (where to seek treatment and services for translation and patient navigation throughout the community and local organizations) - Challenge negative beliefs about screening and learning about results with anecdotes and published data on screening benefits - Practice communication with medical providers (role-playing) - Practice goal setting and self-monitoring as effective techniques for improving diet and PA - Highlight culminating event to facilitate behavioral strategies of (goal-setting/self-monitoring) aimed at engaging entire community - Employ local, culturally sensitive partnership and support where possible - Educate healthcare providers about Navajo culture and appropriate communication and activities - Educate healthcare providers about our program as a resource for their patients	- Review individual and familial structural barriers and ways to address them - Match patients with appropriate local site even if care is received in urban setting (expecting more sites in full project) - Engage in personalized goal-setting based on individuals' activity level with all family members - Stepwise approach to reach ACSM cancer survivor exercise targets - Be a resource on signs and symptoms for reducing activity/stopping activity/seeking consult with program and/or healthcare provider - Review home-based program activities based on activity monitors - Practice communication with health provider one-on-one for issues participants are not comfortable discussing in group setting - Reinforce progress towards individual and family goals and ability to self-monitor progress - Facilitate individuals identifying optimal program for them including: activity choices, group vs. solo activities, and home + center or another site

(Contd.)

Theoretical Construct	Intervention Objectives	Strategies for Activity or Group Sessions	Strategies for Individual Activities
Nurturers (PEN-3) (Supportive and/or discouraging influences of families and friends including eating tradition, community and events, spirituality and soul, values of friends)	- Reinforce the value of healthy traditional foods and PA in cancer prevention, prevention of other chronic disease, and overall quality of life - Reinforce cultural beliefs of restoring balance and aerobic PA - Emphasize importance of and provide skills needed to seek social support at the family and community level - Reinforce the importance of information about cancer for family and community members, including appropriate PA recommendations for survivors	- Discuss cultural aspects of balance, health, physical activity, and dietary habits - Share real-life examples of coping strategies gathered from the qualitative study in Navajo cancer survivors - Facilitate social support of fellow participants due to shared experiences and success/learned lessons; draw on prior successes - Reinforce the cultural value of gaining knowledge for dissemination to other family members (who are generally at elevated risk for cancer) and other members in the local community	- Reinforce ability and importance of seeking and providing support - Provide individualized and family education based on cultural and clinical knowledge of cancer - Review success in employing coping strategies
Perceived Susceptibility (HBM)	- Reinforce accurate beliefs about susceptibility and decrease prevalence of inaccurate beliefs - Reduce fatalism about diagnosis and provide more optimistic view	- Provide and discuss culturally and clinically relevant educational materials about susceptibility, screening, and PA recommendations for cancer survivors - Disseminate materials throughout local community organizations and leadership as well as within the family	- Review knowledge of PA recommendations during and after treatment (back-teaching) - Review benefits of activity for each individual and their family members based on type of cancer
Perceived Benefits (HBM)	- Improve knowledge on the role of PA for several different cancer types and in recurrence for several cancers - Improve knowledge on the benefits of PA for fatigue and quality of life among family and community - Improve knowledge on the importance of early detection and following treatment and screening recommendations for patient and family members - Improve knowledge of adequate intensity required to achieve protective benefits	- Provide culturally appropriate education to survivors and family/community members on the importance of activity for cancer prevention, control, fatigue, and quality of life - Group discussion on benefits of early detection - Group discussion on health behaviors currently engaged in/successful changes made in the past	- Reinforce accurate individual and family beliefs - Challenge inaccurate beliefs - Review individual list of pros and cons and emphasize individual reason for engaging in healthy behaviors and personal control
Perceived Severity (HBM)	- Increase knowledge on cancer survival rates, advances in treatment, and the importance of early diagnosis and therapy - Provide information that although cancer is a serious condition, survival rates of many cancers have improved, particularly with early diagnosis and adequate treatment	- Participants develop a list of pros/cons of engaging in regular screening, PA, and healthy/traditional diet - Discuss reasons and consequences of engaging in healthy behaviors	- Challenge inaccurate beliefs - Reinforce accurate beliefs through education via teaching, one-on-one conversations, handing out fliers, and encouraging participants to ask questions

(Contd.)

Theoretical Construct	Intervention Objectives	Strategies for Activity or Group Sessions	Strategies for Individual Activities
Self-Efficacy (HBM)	• Increase self-efficacy for secondary cancer prevention among patients, family members, and at organizational/community level • Increase self-efficacy to engage in behavioral strategies of PA and other health behaviors • Increase sense of self-control and self-determination at the community level to improve quality of life and cancer fatigue • Increase ability to seek and utilize resources, including social support of peers, family, and community members • Empower participants to take control of their own and families' health • Reduce anxiety or discomfort associated with changes among patients, family members, and community members • Emphasize opportunity for participants to improve experiences of other family/community members	• Provide information on baseline activity status and progress towards goals • Share successes at the group level and among family/community • Offer direct encouragement and positive verbal reinforcement during on-site sessions • Draw upon the camaraderie of group sessions to motivate individuals • Group discussion on successes achieved to overcome health challenges (e.g., treatment side effects) during and post-treatment • Group discussion on influencing family and community members in a positive way with encouraging PA	• Positive reinforcement of healthy behaviors; draw upon strengths and successes • Encourage open and honest communication about challenges, successes, and progress

Table 3: Culturally sensitive elements and dimensions incorporated into PA intervention for Navajo survivors.

Intervention ^a	Culturally sensitive elements	Restoring Balance PA Program
Language	Culturally appropriate; culturally syntonic language	• Bilingual students and staff, including bilingual Navajo healthcare worker with deep cultural knowledge to facilitate introductions to the intervention and explanation of the PA program and protocol, consent, and to follow-up with participants throughout the intervention • Questionnaires were modified to include cultural activities/terms and eliminate irrelevant activities/terms • Intervention materials are developed in Navajo language and different formats (print, video) to be accessible to all family and community members
Persons	Role of ethnic/racial similarities & differences between client & staff in shaping study relationship	• Native students and staff on intervention team • Partnering with Native serving wellness facility for on-site sessions and at-home remote coaching and goal setting • Native community action committee, Navajo Nation Human Research Review Board, Navajo Chapter House, Navajo Regional Agency Councils, Native university faculty and leadership for advice and support • Include family members in intervention • Engage with local community organizations to discuss programming at community level
Metaphors	Symbols & concepts shared with the population; sayings in intervention	• Native introductions and motivational sayings in introduction to study and in program materials • Train Navajo local trainers to deliver program to build capacity and serve as role models • Name, logo, and materials incorporate valued natural elements, traditional activities, concept of balance • Logo elements include: feathers for blessing and curing; 12 dots for time – days and nights; spiral for four ages of life (infancy, youth, middle, old age); sky band leading to happiness; and feet for walking, which was the most common form of exercise in the qualitative analysis
Content	Cultural knowledge: values & traditions; uniqueness of groups (social, economic, historical, & political)	• Traditions of running, walking, dancing, tending livestock and land for aerobic components • Regional SES, history, and politics informed site expansion to trusted Native focused sites which improved proximity, positive community relations, sustainability potential, and incorporated Native employees • Cultural values such as peace, balance, and harmony incorporated in PA intervention • Varied preference for community vs. at-home and group vs. individual program, thus incorporated flexibility to meet any of these preferences • Each participant can tailor to individual exercise preferences and surroundings in consultation with site trainer (e.g., herding sheep, running on open land on the reservation, etc.) • Family and friends of the cancer survivors invited to participate in the intervention program alongside survivors to enhance support and reduce perspective of cancer as a contagion • Provide materials to easily disseminate content throughout the community and foster sustainability

(Contd.)

Intervention ^a	Culturally sensitive elements	Restoring Balance PA Program
Concepts	Intervention concepts consonant with culture and context	• Blending of within culture aerobic activities with additional cancer exercise recommendations for resistance training • Focus on the positive effects of PA rather than cancer, which is not a culturally desirable discussion topic • Culturally specific motivations for PA, such as “restoring balance” to life, incorporated in intervention materials, rather than other motivations for PA (e.g., weight loss) • Program named “Restoring Balance” • Focus on the value and uniqueness of tribal kinship and importance of family and community support
Goals	Transmission of positive and adaptive cultural values; support adaptive values from the culture of origin	• Celebrates and supports Native resilience, resourcefulness, seeking balance in life, especially post-trauma (i.e. cancer and cancer treatment) • Partially removes barriers to family and community support for survivors by including family/friends in the program • Support Navajo cancer survivor value to help prevent cancer in others through education for community on cancer risk factors, screening, and prevention through outreach materials and inclusion in the intervention
Methods	Development and/or cultural adaptation of intervention methods	• ACSM cancer exercise guidelines culturally adapted using PEN-3 and Health Belief (HBM) models to understand PA among Navajo survivors and inclusive of elements above • PA recommendations for types of activities and settings were modified to fit cultural preferences, habits, and environment (i.e., outdoor walking, home resistance exercises, etc.) • Select community organizations were found to be trusted, so these sites will be used for delivering the PA intervention, such as tribal serving health clinic or local community Chapter House • Native and Native serving staff and students will be trained to expand scope of practice to cancer exercise and will be used to deliver the intervention • Local training to support local community to sustain the intervention once the study is complete • The Navajo language will be used in the intervention phase during recruitment and follow up with participants
Context	Consideration of changing contexts in assessment during intervention: social supports and relationship to tribe; economic and social context of intervention	• Community based program, inclusion of family and friends, to combat reported social isolation • Free intervention with reimbursement for time and travel in addition to building of community capacity to ameliorate travel/environmental barriers to PA and promote sustainability in locations proximal to survivors • Sites with good tribal relations selected and research team active in communication with stakeholders and maintaining good tribal relations to address mistrust of Western medicine among some survivors and community members

^a Adapted from Bernal, Bonilla & Bernillo, 1995.

moderate and vigorous physical activity, as appropriate. Although these are not generally leisure-time activities, we felt it would have been a missed opportunity not to gain insight into whether survivors engaged in these moderate/vigorous activities known to be common among Navajo people. **Cultural preferences for PA.** PA recommendations for types of activities and settings were modified to fit cultural preferences, habits, and environment. Specifically, this included an outdoor

walking program and home resistance exercises that used household items and portable, inexpensive equipment to enhance adherence and sustainability.

PA program elements. Based on recommendations from focus group and interviews and the varied preferences conveyed, the PA program was designed to have both a community site element and an at-home element in addition to a group-based activity time or individual activity time.

Family and friends. Family and friends of the cancer survivors were invited to participate in the intervention program alongside survivors as a way to enhance support. As stated previously, some cancer survivors may have experienced decreased interaction with family and friends due to the belief that cancer is contagious. By inviting the community to participate with cancer survivors and learn about cancer etiology and PA benefits, this belief may begin to change.

Motivational mindset. Interview participants also reported culturally specific motivations for PA, such as “restoring balance” to life, and returning to harmony with the world around them. These sentiments were used when creating intervention materials, rather than other motivations for PA (e.g., weight loss). Further, the public name for the intervention became “Restoring Balance.”

Navajo healthcare workers. The utilization of a Navajo healthcare worker to facilitate participant recruitment and communication was an essential component of intervention design. Qualitative analysis revealed mistrust between several Navajo individuals and Western medical professionals. Thus, the inclusion of Navajo healthcare workers was seen as an indispensable aspect of the intervention from recruitment to retention efforts.

Choosing a community health partner. A community health partner that serves the Navajo population was chosen to assist in delivery of the intervention. There were several reasons for this decision: (a) the partner had an established network and trust among local Navajo individuals, (b) focus group participants indicated that they would be more comfortable engaging in exercise when surrounded by individuals like them for support, (c) the creation of a sustainable PA program for Navajo cancer survivors is a goal of this intervention, and (d) a Federally Recognized Urban Indian Health center is ideally suited to continue the program. In addition, the community partners chosen will have increased capacity to sustain and build upon the intervention program via training local staff specifically in cancer survivor exercise through the American College of Sports Medicine.

Culturally specific materials. Qualitative analysis also revealed a need for education about PA, cancer, and cancer survivorship. Thus, the development of culturally specific educational materials was included into the intervention design. These materials can also be shared in community outreach efforts.

Support staff. Numerous stakeholders were identified, and it became clear that continuous communication with all involved would be an essential component of intervention success. A portion of the intervention budget was allocated for the hiring of support staff to assist with communication and organization.

Planning Implementation

The dispersed geographical area and low population density of the Navajo Nation was identified by stakeholders and qualitative study participants as a potential challenge to participant recruitment and retention. They recommended recruitment at organizations or events that focus specifically on the Navajo people and/or cancer care. Recruitment eligibility and trust would be enhanced by these foci. The small number of sites available for participating in the study was another limitation to recruitment cited. If potential participants do not have a reliable means of getting to the limited sites, participation would be hindered. Therefore, setting up a reliable means of communication between investigators and participants for recruitment and during the program was noted as a key element for survivor engagement.

The need for flexibility within the intervention design to reflect long travel times to the community health center, and often, ongoing treatment and multiple other medical appointments was required in planning the intervention. The intervention will include in-person supervision of PA combined with home support by phone to ensure participant-investigator interaction between visits, to maintain goal setting, and optimize adherence. Further, Native staff at the clinic will be made available as often as possible to escort participants from their regular oncology visit to the wellness center for intervention consent, measurements, and initiation of the program. Native staff will update contact information frequently to ameliorate loss to follow-up due to disconnected numbers or lack of email review. The study baseline survey will include a request for contact information for someone close to the participant, which can help study staff locate the participant should they move or change phone numbers. Finally, frequent travel to the tribal nation for follow-up communication with participants will be conducted by Native staff, spanning a broad range of hours and days of the week to accommodate participant work schedules and travel constraints.

Ideally, with scientific rigor in mind, all PA would be performed on-site and recorded by the investigators. However, to accommodate the needs of the population, practical measures, such as giving participants the flexibility of completing their PA either on-site, at another outside site, or at home, are required and will be implemented. In addition, participants will be given the choice to participate in groups or individually. Although these measures may reduce control, they will likely contribute to the feasibility, participant retention, and success of the study overall. To enhance rigor, measures completed on-site will be repeated for accuracy and off-site activity will include recorded goal setting, activity logging, wearable activity monitors, technical support, and follow-up calls and coaching.

Other measures to enhance flexibility of the intervention include individually tailoring PA to current fitness levels and health status while working one-on-one with a local trainer at the community health center. To assess feasibility of the overall program, the intervention will begin with a small pilot study in one urban and one reservation-based location. If successful, the pilot will be expanded to multiple locations to serve a broader population.

Assessment of Efficacy

Success of the pilot study will be based on several factors: (a) recruitment, (b) adherence, (c) retention, and (d) participant satisfaction. Secondly, improvement of outcome measures will be assessed. Subjective feedback on the project from the community health center and other stakeholders will be solicited. Based on an evaluation of these factors, the intervention will be modified and improved for implementation across a broader population and powered to fully test efficacy.

Discussion

The purpose of this manuscript is to describe the development of a theory-based, culturally appropriate intervention focused on promoting PA among Navajo cancer survivors. The disparity in cancer survivorship and lack of research on PA among Navajo cancer survivors served as a catalyst for this process. The IM approach allowed for an organized approach to intervention development. The theoretical models bolstered IM, allowing for comprehensive consideration of needs, stakeholders, and specific cultural factors relevant to the proposed intervention.

Current literature describes the cancer health disparities in Native American populations but does not address the potential benefits of PA in cancer survivorship, nor the design and application of a culturally relevant PA intervention in Native American cancer survivors. A literature review brings to the forefront studies that employ IM as a tool for increasing breast and cervical cancer screening and prevention behaviors among Hispanic (Byrd et al., 2012; Fernández, Gonzales, Tortolero-Luna, Partida, & Bartholomew, 2005; Scarinci et al., 2012) and African American women (Highfield et al., 2015). Only one study used the IM approach among Native American women; it used culturally appropriate elements, such as talking circles, to advance cervical cancer screening and prevention (Hodge, Fredericks, & Rodriguez, 1996). Additional studies have been implemented within the Native American population related to diabetes and obesity (Diabetes Prevention Program Research Group, 2002; Rubin et al., 2002), such as the Pathways study (Davis et al., 1999; Going et al., 1999). Our study adds to the current literature by implementing both the already proven methods for improving cancer survivorship through PA and IM in a Native American population.

Numerous lessons were learned throughout the project that are pertinent to organizations intending to work with the Navajo, as well as researchers intending to develop interventions among cultures different from their own. Perhaps most vital to success is building trust among the community and all stakeholders. It was essential that the efforts of this research team were not seen as transactional in nature, but that there was a true desire to engage with the community to understand the nuances of their culture and needs. To this end, the engagement of a broad range of stakeholders including tribal review board, community organizations, and the Navajo cancer survivor participants in the qualitative study were vital to mapping the intervention and building the infrastructure for implementation. They helped to ensure that all aspects of the intervention design will resonate with the Navajo population, and without their engagement, effective communication, trust, and recruitment will not be possible.

Additionally, flexibility in the intervention design was identified as important for this population. Many participants had long travel times to any community gather places, care providers, or wellness sites. Several intervention participants are expected to require ongoing post-surgical cancer treatment, resulting in numerous weekly appointments, as well as dealing with the debilitating side effects from medications. In sum, the lessons learned included:

- engage multiple stakeholders,
- plan for recruitment challenges,
- importance of building trust,
- importance of community health workers,
- need for flexibility among this population, and
- tension between practicality and scientific rigor.

Strengths and Limitations

As mentioned, the community was engaged in the design of the planned intervention. Various cancer types, and their unique challenges, were included in the survivor perspectives, as were both males and females. Though the qualitative study that predominantly informed on intervention design was relatively small and included more females than males (60% vs. 40%), it represented a significant proportion of the population given the stringent geographic, demographic, and cancer diagnosis eligibility criteria. The sample size is also consistent with previous literature (Browne, 1995). In addition, the use of leisure-time PA measures may have limitations in this population (for example, due to the limited availability of commonly used leisure-time activity facilities), as does the use of self-reported PA in general (e.g., Sallis & Saelens, 2000).

The process of IM in this study revealed areas of need in the Navajo cancer survivor community, specifically a need for education on cancer and PA recommendations. Exploring these areas through the lens of IM only just begins to describe and document the experience of Native Americans living with cancer, let alone Navajo living with cancer. There is an urgent need for further studies and exploration of cancer survivorship in Native American communities, and it is the goal of this research team to conduct and to inspire further investigation within this population.

Conclusions

Despite improving cancer survivorship rates throughout much of the U.S., significant disparities exist between Navajo and non-Hispanic White cancer survivors. Based on qualitative analysis, there is a need for Navajo cancer survivors to have increased access to PA programs and education about cancer, cancer survivorship and exercise. The development of a theory-based, culturally relevant intervention may help to reduce these health disparities. This paper outlined the development of a PA intervention for Navajo cancer survivors. Pilot testing of the feasibility and effectiveness is currently underway for the PA intervention derived from the IM process.

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Competing Interests

The authors have no competing interests to declare.

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