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The cultural constructs of cancer-related fatigue among American Indian cancer survivors

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Abstract

Purpose Cancer-related fatigue (CRF) is a common symptom experienced by cancer survivors. Persistent fatigue can last years after cancer treatment. CRF's origin is unknown, and there are no validated treatments. Cultural constructs (definitions, meaning, and explanations) may vary the presentation and treatment choices related to fatigue. Identifying and categorizing CRF terms and experiences among racial, ethnic, and non-English speaking groups may provide a fuller understanding of CRF to guide tailoring of interventions. We report on the cultural constructs of CRF as reported by American Indian cancer survivors.

Methods A study of Southwest American Indians collected qualitative data on cancer survivors' experiences of fatigue. Focus groups ($n=132$) at urban clinics and rural reservation sites in the Southwest collected qualitative data on cancer survivor experiences with fatigue. The sessions were audiotaped and transcribed verbatim. During analysis, common themes were coded and formed into categories following Grounded Theory analytical procedures. Relationships between categories were examined.

Results CRF was described by survivors as an entity that comes into the brain, "drains life" from the body, and creates long-lasting suffering, pain, and stigma. We review the

cultural constructs of fatigue and CRF's relationship to "being out of balance."

Conclusions There is a need for culturally appropriate education concerning fatigue, techniques for reducing fatigue, and support for American Indian cancer survivors and other vulnerable populations.

Keywords Fatigue · Cancer-related fatigue · Symptoms · Cultural constructs · American Indian

Introduction

Cancer survivors report cancer-related fatigue (CRF) as feeling weak and tired, too worn-out, and depleted of energy [1]. Cancer-related fatigue is the most common side effect of cancer and its treatment [1]. Studies report that over 90 % of cancer patients experience fatigue, and its prevalence can vary depending on cancer type, stage, and treatment [2]. Cancer-related fatigue significantly impacts survivors' ability to perform normal daily activities [3]. Although loosely described as the "general feeling of debilitating tiredness or loss of energy" [4], fatigue assessment scales have not been sufficiently psychometrically tested [5, 6]; thus, the severity of fatigue cannot be adequately measured quantitatively, as the scales do not account for the patient's perception of fatigue [7]. Fatigue scales often simply rely on the patients' self-report, resulting in multiple interpretation of the scores [7–9].

The onset of CRF is usually sudden, not resulting from activity or exertion, nor relieved by rest or sleep [10]. Most simply, cancer survivors describe CRF as "paralyzing" [11]. The underlying physiologic causes of fatigue are poorly understood [3, 12] as CRF may have more than one underlying cause. The National Cancer Institute (NCI) suggests that CRF causes span from not sleeping well or stress-related to physical

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ailments, such as pain, anemia, and problems in breathing, walking, or functioning in daily activities [13]. Additionally, the loss of blood, skewed hormone levels, infection, and dehydration may exacerbate feelings of fatigue. A growing body of literature suggests a link between both cancer and cancer treatments and inflammation that contribute to CRF. Individual genetic and immune system alterations combined with bio-behavioral factors such as sleep, depression, body mass index, and stressors in early life may be associated with variations in experience of CRF [14].

Cancer-related fatigue can be acute or chronic and can persist for years after cancer treatment is completed, negatively impacting quality of life and functionality [15]. Fatigue may persist and often gives rise to serious comorbidities, such as depression, anxiety, and pain (as previously mentioned, pain may also cause fatigue) that also significantly affect quality of life [16, 17]. Additionally, studies have found CRF has a strong correlation to physical and mental stress [18].

The burden of CRF often disproportionately affects minority populations because among these groups, CRF is seldom discussed and infrequently treated despite its high prevalence [19]. As stated by Aziz and Rowland (2002), survivorship research related to cancer healthcare delivery, access, and follow-up care is particularly under-researched for minority populations, including American Indians, and a better understanding of the impact of healthcare delivery and access, as well as cultural appropriateness and acceptance of care, is needed [20]. Budharani (2014) also asserts that race/ethnicity should be included as an essential component of comprehensive symptom assessments in survivorship care [21]. Due to the dearth of information about cancer-related fatigue among American Indians, native survivors residing in the Southwest United States were recruited for this study due to high rates of several cancers among this population [22].

A lack of communication between clinicians and patients about CRF may be problematic for fatigue management and may be attributed to multiple factors, including poor patient-provider interactions [23], the failure of cancer patients to report their fatigue experience [24], as well as provider-patient concordance and discordance during the communication phase which may alter the information exchange required to make diagnosis [25]. The patient's lack of awareness of fatigue treatments, the desire to treat fatigue without medications, and a tendency of the patient to be stoic about fatigue to avoid being labeled as a "complainer" [26] may also impede communication surrounding CRF. Additionally, perceptions of CRF as an unavoidable side effect of cancer can pose a barrier to management. Thus, identifying and responding to cancer survivors' needs requires a better understanding of the fatigue phenomenon for appropriate interventions, exploring barriers to reporting fatigue in cancer patients, and the significant factors associated with those barriers from fatigue characteristics (i.e., intensity, duration, and interference with daily life), to

demographic characteristics and disease/treatment variables. This paper explores the experience of CRF as reported by American Indian cancer survivors in the Southwest, and we report on three themes derived from focus group sessions: etiology, experience, and presentation effects of CRF.

Methods

One hundred and thirty-two (132) American Indian adult cancer survivors and their family members participated in 13 focus group discussions on cancer symptom management. The majority of participants were female (95 females, 37 males). Inclusion criteria were (a) American Indian, (b) age 18 or older, and (c) a cancer survivor or family member or caregiver. Focus groups were held at reservation sites in the state of Arizona and at urban clinics in Phoenix and Tucson. The sessions, 1–2 hours in length, were audio-recorded. Thirty-five dollar gift cards were offered to cover travel and participation expenses. Focus group discussions centered on the cultural constructs and personal experiences with cancer, cancer symptom self-management, and cancer beliefs, myths, and fears. Six major questions were asked during the focus groups, guided by facilitators using pre-determined prompts, allowing for open-ended discussion until subject areas of research interest were saturated. The six questions asked were the following:

1. Tell me about your experience with being tired (fatigued), the fatigue that you have when you have cancer. Did you notice that you felt tired as a cancer patient?
2. Can you describe that kind of being tired because there are different types of being tired?
3. What did you do for your fatigue? Did you take anything or do anything for your fatigue?
4. What problems or barriers did you experience because you were fatigued?
5. What do you think caused your cancer and your fatigue?
6. What are your fears about cancer and fatigue?

Information was gathered on participants' experience with CRF. Additional information regarding the study sample distribution of ages, income level, education, level, cancer type, etc. may be found in the literature [26]. Each participant was consented prior to enrolling by the project facilitator. The study received Institutional Review Board (IRB) approval from the University of California, Los Angeles and the Phoenix Area Indian Health Service IRB.

Analysis

Audio-recordings of focus groups were transcribed verbatim by research staff. Analysis used constructivist Grounded

Theory techniques to identify major codes and categories in the data. Transcripts were read in their entirety by one investigator and then excerpt-by-excerpt coding was conducted to capture the meaning expressed in each excerpt. A qualitative data analysis software (ATLAS.ti) was used to categorize data and to manage the developing themes. Codes were reviewed and grouped by relevance to research questions, similar concepts, and frequency in order to identify major themes emerging from the data. Community representatives evaluated the developing framework to assess accuracy of interpretation and provide validation of codes and themes. A second investigator independently reviewed the categorized codes and key themes. Code description and categorization were discussed and modified until agreement among the entire research team was achieved.

Results

Among Southwest American Indian cancer survivors, CRF was described as a process of “being out of balance” and an experience that “drains life” and creates long-lasting suffering, pain, and stigma. Self-management or treatment activities were reported as a mix of techniques to energize, bringing the body and mind back into balance, and over-the-counter (OTC) medication (see Table 1). Several important themes developed within the following three major categories: etiology, experience, and effect.

Etiology of CRF

State of “out of balance”: Cancer-related fatigue was explained by participants as being “out of balance” with the natural pattern of life, which is dependent upon harmony and equilibrium both internally and externally and is highly valued in American Indian cultures [25]. Internal balance encompasses individuals’ physical and mental state, and its disruption results in fatigue. “Not having enough rest, not exercising, not eating healthy” were described as leading to

fatigue, according to one survivor. Another felt that CRF was likely caused “by stressing yourself out.” Negative emotions were perceived as leading to a shift in the balance of life, as an imbalance in any single aspect intended to maintain a healthy balance can tilt to become skewed, troubled, fatigued, and ultimately sick. Factors affecting external balance relate to family and community life. Inappropriate activities, such as breaching taboos (in terms of requisite behaviors in social gatherings, interactions, and conduct), language expression (e.g., respectful acknowledgement), and failure to attend to traditional activities (e.g., cleansing ceremonies, dances, and seasonal events) could impact a survivor’s fatigue. Such behaviors (or lack thereof) were seen as not taking care of one’s body and mind, thus having an impact on one’s state of health, resulting in fatigue. The need to participate in cultural and community activities can be stressful, as the non-activities of the cancer survivor were viewed negatively within the larger lens of the family’s activities. Cancer survivors may appear healthy, and CRF may not be noticeable or may be seen as being lazy, disrespectful of the community event, or unfamiliarity with the cultural activity. Being out of balance may cause one to be “un-well,” and this state may result in physical and/or mental illness presented as fatigue, stress, and suffering.

Fatigue resulting from cancer diagnosis and treatment As the cancer diagnosis almost always comes with the “dark cloud” (quoting one cancer survivor) of fatigue, treatment recommendations for cancer care were explained as causing the resulting fatigue by a number of participants. The cancer diagnosis adds an element of stress and confirmation of “unwellness.” Adding perceived harmful elements into the body (such as chemotherapy and radiation) are believed to contribute to being un-well and unbalanced. A poor prognosis often leads to “bad thoughts,” and the cancer treatment poisons the body that is particularly vulnerable in an “unbalanced” state. One cancer survivor stated, “I was really fatigued more when I was taking my chemo,” echoed by another participant’s comment that, “...after the treatments [the cancer survivor] just

Table 1 Focus group perception of CRF cause, experience, and effect

	Description	Physical event	Consequence
Etiology	“Out of balance.”	“By stressing yourself out” may have “done something” wrong, or not taken care of their health, thus they “caught” cancer.	Pain and suffering... “you hurt a lot more [because of fatigue].”
Experience	“...fatigue is when you are drained and stuff. It is like brain tired.”	“Not having enough rest, not exercising, not eating healthy.”	“Yeah, that was after the treatments. Just tired and wore out; no energy to do anything.”
Presentation	CRF is “a disease-like entity that comes into the brain and ‘drains life’ from the body.” “It is like brain-tired or something - not physical fatigue but your brain’s fatigue.”	“I’m tired and I might be irritable.” “I was emotionally drained and I thought that was a sign of depression, I didn’t do nothing; I didn’t even eat.”	I think fatigue is gonna always be there as long as you’re sick, I don’t think that it’s going to leave you.”

tired and worn-out; no energy to do anything” ... “would come home from the chemotherapy...looked wiped down” and “exhausted.”

Presentation and experience of CRF

Fatigue defined: Cancer-related fatigue was described by survivors as a disease-like entity that comes into the brain and “drains life” from the body. “It is like brain-tired or something...not physical fatigue but your brain’s fatigue - when you have issues and stuff,” referencing cognitive issues related to fatigue. Once diagnosed with cancer, the fatigue and lethargy is characterized as relentless. Participants shared that fatigue becomes a something of a constant companion – a partner in the struggle with cancer – that seldom is resolved. Cancer and fatigue become interchangeable – as each becomes inseparable in the survivors’ experience. Participants described CRF as never leaving the body until one passes into the next life. “I think fatigue is gonna always be there as long as you’re sick, I don’t think that it’s going to leave you,” stated one survivor.

Presentation effect of CRF

Further illustrating the draining impact of CRF, the survivors described physical well-being deteriorating and their bodies as being continually “worn-out.” In the fatigued state, “the body cannot heal,” nor can it “function well.” Characterized as “weakened,” a fatigued “body sleeps with little or no rest.” The lack of rest and sleep results in brain “confusion,” forgetfulness, and listlessness that does not end. The emotional drain leads to depression, introspection, and disinterest in relationships with other people, social, and American Indian community activities: “mentally like you cannot - just don’t want to do nothing. You don’t get out of bed and even if the phone rings, you don’t want to answer it. It is emotional fatigue, you just want to sleep it off, or something like that, sit there and be a couch potato for the rest of the day or something.” “Sometimes I am sitting there and I know I have to get up,” “I know I want to take a shower, I want to cook, but I cannot – I want to stay in bed.” Other participants shared feelings of depression and the lack of interest in recreation: “I couldn’t go out; I’m tired.” Another shared, “when we try to go out we end up just...it’s not a good time. I’m tired and I might be irritable.” “I was emotionally drained and I thought that was a sign of depression. I didn’t do nothing; I didn’t even eat.”

Not feeling well and being tired all of the time impacted emotional health as well, reportedly creating irritability among survivors. “I’m just tired. I get myself so worked up.” Feelings of discomfort and grumpiness caused by the all-encompassing exhaustion were expressed: “I feel uncomfortable, impatient, like I know that I couldn’t stay there, but I know that I could not be up doing things.”

Comorbidities with CRF

Pain: Not unexpectedly, the experience of CRF caused cancer survivors a great deal of suffering. While entirely different entities, fatigue can exacerbate the perception of pain, another common cancer symptom; as one survivor pointed out, “you hurt a lot more [because of the fatigue].” The pain does not go away – some describe it as “long-lasting suffering and pain.” One survivor stated, “I always hear people say that they are tired, and now I see that one of the things is pain, and one of the other things [along with fatigue and cancer] is treatment - they’re combined.” Another shared, “the chemo was throwing down all [of the survivor’s] body” so that the pain was “constant” and “limiting movement.”

Stigma of CRF: One of the most tragic consequences of experiencing CRF among American Indian survivors was the stigma associated with the survivor appearing to be lazy or not trying to maintain daily activities. Many survivors admitted considering themselves at fault. One male survivor shared, “If I am lazy, I would feel guilty – man, get up and do something - but if you’re fatigued - that is something overwhelming to me, you don’t even think about what everyone thinks. It is exhausting.” Family and community perceptions of survivors as lazy were also described: “when we went through fatigue, no one realized that it was not because [the survivor] is lazy, it’s because [the survivor] is dealing with this thing called fatigue.” A caregiver shared, “I think of how the chemo was in part, due to his personal behaviors, such as not living a good life or taking care of your body.” Victimization was almost always a part of the vocabulary used in describing fatigue. The theme that the survivors may have “done something” wrong, or had not taken care of their health, thus they “caught” cancer and the subsequent fatigue that is often paired with cancer. Another survivor reported feeling pressure to “resign to living with constant fatigue without relief.” Yet another shared that there may be an expectation that “one does not talk about it” so as to “not burden others,” as “Nobody knew it; I didn’t tell anybody I had it. I just kept it to myself.”

CRF self-management

Cancer-related fatigue treatment activities: Self-treatment activities were reported as a mix of techniques to energize, bringing the body and mind back into balance, and OTC medication. One participant instructed “Taking time to yourself to get yourself energized so you can help somebody else. Probably take a minute to yourself no matter what.” Another recommended, “to be well, one must regain the proper balances in life,” with regard to taking care of one’s physical, mental, emotional and spiritual health. Yet another shared, “I try to keep myself to positive thinking; that really helped.” Another

stated, “I don’t try not doing anything” as she got up every day to do “something.”

Survivors shared that they take OTC supplements and medications, such as vitamins and aspirins to counteract their fatigue. One shared, “the doctor gave me Vitamin B and he gave me the fish oil and another supplement that has iron in order to help me, because lately I’ve been tired.” Another instructed “because when you’re tired you can rest your body by sleeping and taking medicine,” therefore both could be used to help out as needed. Survivors felt it was important that the meaning of wellness and un-wellness be understood, as living a life that does not have excesses and that balances the physical, mental, emotional, and spiritual aspects of daily living is desired. These are important concepts in American Indian culture and they served as guiding instructions for participants.

Discussion

The literature reports varying treatments for CRF, but due to the culturally influenced experiences of American Indian cancer survivors, treatment plans for this population may also necessitate cultural tailoring to be effective in improving quality of life. As with other studies, participants understood that CRF was hard to treat and did not respond to rest. Our research concurs with the literature that support from family members and providers may be improved with education and the knowledge of the impact of CRF that often results in pain, suffering, and stigma [27, 28]. The perception of a fatigued survivor need not carry the stigma associated with fatigue. Although few participations knew that the cancer itself can cause fatigue (“I never did know that fatigue was one of the symptoms”), they understood that in the fatigued state “the body cannot heal,” nor can it “function well.”

The lack of knowledge regarding cancer etiology and cancer-related fatigue was voiced by many participants. American Indian cancer survivors noted their lack of knowledge about the singular and combined symptoms of cancer. Survivors voiced a concern that they were not provided full or adequate information by healthcare providers on their cancer. They felt that information such as the type and stage of cancer, treatment recommendation(s), why such treatment was selected, and the potential adverse effects of the cancer treatment were not shared during their medical appointments or treatment regimens.

The lack of reporting CRF as a cancer symptom and its debilitating impact were common themes across all focus groups. Cancer-related fatigue was reported to have a negative effect on family members and caregivers, most significantly impacting roles. Understanding that CRF might be inevitable and is a manageable cancer symptom is an important message for survivors, as well as family members and caregivers who

often have to adjust their roles in response. Gaining a better understanding that fatigue is a cancer symptom, and how to manage CRF were learning goals for the project participants.

Improving communication with providers is essential to the healing process. Cancer patients, survivors, and family members want to improve communication with their healthcare providers and others, and staff can and should be trained on cross-cultural communication and cultural competency. Healthcare providers should be educated not to automatically assume that patients who are not asking questions about fatigue do not understand or do not want additional information; for most participants in our study, the consensus was that they could understand what the doctor tells them and they would listen to their instructions, especially if cultural facets were emphasized.

More attention is needed for American Indian cancer survivor advocacy. Survivors themselves can be their own best advocates, but the support of their family, friends, community, and the medical care staff is critical for the best chance of healing. Improving advocacy can mean many things, such as offering general education and information to family members, guidance and support with healthcare decision-making for patients, assistance with daily activities and health care procedures, counseling, building a liaison with medical providers, other services, and even just providing companionship for patients/survivors. Together, survivors and their healthcare providers can work to improve self-management of CRF to reduce pain and suffering and to improve survivor’s quality of life.

Implications: Understanding the cultural constructs of fatigue as “being out of balance” and state of “un-wellness” can help providers to assess their American Indian patients. Bringing the body and mind back into “wellness” and “balance” can be a team effort. Targeted education is needed for those who are unaware of CRF and its impact on daily functioning. Knowledge of CRF as a cancer symptom can support self-management and can aid caregivers/family members. Stigmas associated with survivors feeling they are viewed as “lazy” or “no use” can be lessened by increased patient and family education. Cancer-related fatigue has a long-lasting impact on one’s health and functioning, including cognitive impairment and depression [29].

Because CRF’s origin and efficacy vary for each patient [30], the need for culturally appropriate techniques for reducing fatigue and support is great given the disparity reported for cancer prevalence and under-treatment among vulnerable populations. Like many indigenous groups, American Indians represent over 500 tribes, with several languages and holding varying degrees of cultural constructs regarding cancer etiology and CRF. Tribal and urban groups in the Southwest may be the same or differ from other tribes and regions in the USA. Our research findings and recommendations report only to

those American Indian cancer survivors in the Southwest. Better understanding of CRF experiences in the larger American Indian population may aid in the development of interventions that are tailored for greater potential for improving quality of life.

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Conflict of interest The authors declare that they have no competing interests.

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