

Cancer Journey for American Indians and Alaska Natives in the Pacific Northwest

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Purpose/Objectives: To describe the experiences of American Indian and Alaska Native cancer survivors to improve understanding of the trajectory of cancer treatment.

Research Approach: Qualitative focus group research.

Setting: Rural and geographically isolated American Indian and Alaska Native communities in the Pacific Northwest.

Participants: 30 American Indian and Alaska Native cancer survivors or caregivers.

Methodologic Approach: The authors analyzed data from two focus groups with cancer survivors by using thematic analysis informed by indigenous methodologies.

Findings: Based on focus group findings, the authors developed a conceptual model of the cancer experience called *Rough Waters*. Participants described their cancer experience as a collective journey involving family and friends and requiring resources to offset challenges along the way. Dominant themes were delays, isolation, communication, money, advocacy, spirituality, and family involvement.

Conclusions: American Indians and Alaska Natives in the Pacific Northwest have special cultural needs during cancer care. The current study provides examples that can guide patient–provider interactions.

Interpretation: Using the metaphor of cancer as a journey, clinicians can begin a dialogue to identify what will impede or assist the cancer journey for their American Indian and Alaska Native patients.

Although cancer incidence in American Indians and Alaska Natives (AIs/ANs) is lower nationwide than in the general population, mortality is disproportionately high (Holck, Day, & Provost, 2013; Hoopes, Petersen, Vinson, & Lopez, 2012). Regional variation (Espey et al., 2007; Hoopes et al., 2012; Wiggins et al., 2008) suggests that this high mortality is because of a constellation of nonclinical factors, including cultural, systemic, and economic barriers to care. Distance to oncology treatment centers, inability to pay for specialty care, high cost of transportation, lack of access to cancer screening, and distrust of healthcare providers all make oncology care difficult for AIs/ANs (Burhansstipanov & Hollow, 2001; Guadagnolo et al., 2009; Haozous & Knobf, 2013; Haozous, Knobf, & Brant, 2011; Sequist et al., 2011).

Unfortunately, the barriers that obstruct access to care for AIs/ANs also act as barriers to research, such as perceived poor-quality communication between researchers and participants (Mead et al., 2013). As a result, little is known about their experience of cancer or their perceptions of cancer treatment. For example, a survey of AIs/ANs who underwent cancer screening revealed that they either knew little about their family history of cancer or declined to disclose it in a survey (Schumacher et al., 2008). The same study also found that relatively few