Published in final edited form as:

Support Care Cancer. 2016 June ; 24(6): 2437–2444. doi:10.1007/s00520-015-3041-x.

Satisfaction with cancer care among American Indian and Alaska Natives in Oregon and Washington State: a qualitative study of survivor and caregiver perspectives

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Abstract

Purpose—To better understand satisfaction with care among American Indian and Alaska Native (AI/AN) persons with cancer, we explored dimensions of the provider relationship that contributed to satisfaction among caregivers and survivors who received cancer treatment in Oregon and Washington State.

Methods—Between November 2011 and April 2013, the project team interviewed 11 caregivers and 71 AI/AN cancer survivors residing in Oregon and Washington State. Interview questions aimed to elicit participant experiences with care providers and factors associated with cancer care satisfaction. Interviews were analyzed using an inductive content analysis approach in which concepts were identified and themes derived from interview data.

Results—Three overarching themes, each with two sub-themes, emerged from the data: (1) universal factors: bolstering understanding, involvement, and empathy in care; (2) minority-

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Compliance with ethical standards

Disclosure The content is solely the responsibility of the authors and does not necessarily represent the official views of NIH, NCI, FHCRC, HICOR, NPAIHB, University of Illinois-Chicago, Seattle Cancer Care Alliance, or the University of Washington. The authors have full access to all primary data. Given the ethical standards and protocols with this vulnerable population, primary data may be shared upon approval by the Portland Area Indian Health Service Institutional Review Board and the Northwest Portland Area Indian Health Board.

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

specific factors: incorporating culture and community into care; and (3) AI/AN-unique factors: interacting with Indian health clinics and Indian Health Service (IHS).

Conclusions—The results of our study suggest that satisfaction with care among survivors and their caregivers must be examined within the context of culture and community, particularly among minority patients. Our study demonstrates providers' critical role in ensuring AI/AN patients emerge satisfied with cancer treatment by honoring their AI/AN-specific needs, such as respect for integration of traditional healing modalities and navigation of specialty care coordination.

Keywords

Race/ethnicity; Satisfaction with care; Cancer health disparities; Patient-provider relationship; Cultural competence; Survivorship

Introduction

Cancer is the second leading cause of death among American Indians and Alaska Natives (AI/AN), with AI/ANs experiencing the lowest overall cancer survival rate among all racial/ethnic groups in the USA [1–3]. Inequalities in cancer incidence and mortality between AI/ANs and non-Hispanic whites (NHW) are particularly pervasive [2, 4–6]. Differences in initiation and completion of guideline-concordant care have been proposed as possible causes of these disparities [7, 8]. Satisfaction with patient-provider interactions has been tied to cancer treatment initiation and retention; notably, AI/ANs who access healthcare report lower levels of satisfaction with care than NHW [9, 10]. Determining the components of the patient-provider relationship that facilitate satisfaction is critical to improving treatment initiation and retention and thus health outcomes among AI/ANs diagnosed with cancer [11].

Studies conducted in the USA and other developed countries have shown that providers' ability to build trust, communicate empathically, offer clear and detailed informational support, and establish effective team-based approaches to care are integral to patient satisfaction and adherence [11–15]. Conversely, patients' medical mistrust and inadequate communication between patients and providers as well as within medical teams contribute to lower satisfaction with care [10, 12]. Few studies, however, have captured which factors underlie AI/ANs' lower satisfaction [9].

Under one scenario, AI/ANs may experience lower satisfaction with care due to lower access to universal determinants of satisfaction, including informational and empathic support. These factors influence patient satisfaction and adherence across racial/ethnic lines, including among NHW and other racial/ethnic minority populations [8, 11].

Under another scenario, AI/ANs may have minority-specific factors that are shared with other traditionally underserved groups. For example, some AI/AN communities place a great emphasis on communalism and non-traditional medical sources in health and well-being. Such cultural values and practices are shared with other racial/ethnic minorities, including Latinos and African Americans [8, 16, 17]. AI/ANs may prefer shared decision-making

processes in a manner similar to these groups. Additionally, AI/ANs may have similar preferences regarding providers' familiarity and comfort with their cultural orientation.

Finally, AI/ANs may have AI/AN-unique factors associated with satisfaction, which may be distinctive from NHWs and other racial/ethnic minorities. For example, AI/ANs have unique experiences with access and coordination of healthcare, due to historical eligibility for healthcare services and the design of health systems and services that serve AI/ ANs, including Indian health clinics through the Indian Health Service (IHS) [18].

Simultaneously, AI/ANs have experienced a unique history of racial misclassification and systemic efforts to strip AI/AN identity (e.g., American Indian boarding schools, Last Arrow pageants). Today, AI/AN populations are the only racial/ethnic minority group whose identity is legally questioned (e.g., federal recognition for tribes, one-drop rule membership). These experiences may affect patient-provider relationships, if providers do not incorporate or address AI/ANs' unique access factors or identity needs in recommended care.

Identifying social and cultural factors and experiences with cancer care that are prevalent in AI/AN communities may be the first step to improving cancer care and satisfaction with care among AI/ANs. Such information can inform provider training in culturally astute methods of care as well as providers' planning processes when they begin to engage AI/ANs diagnosed with cancer. Culturally sensitive provider training and planning may result in improved cancer treatment initiation and retention and better satisfaction with care for this vulnerable population. In this manuscript, we report on qualitative data from the Cancer among American Indians: A Multi-State Study (AIMS). Through a culturally relevant, interview-based approach, in this study, we sought to understand elements of the patient-provider relationship that facilitated satisfaction with cancer care among AI/ANs in Oregon and Washington State. Specifically, the analysis was guided by the question: What are the universal, minority-specific, and culturally unique factors that influence satisfaction with cancer care among AI/ANs in Oregon and Washington State?

Methods

Participant eligibility and recruitment

The AIMS project team comprised investigators and staff from the Fred Hutchinson Cancer Research Center (FHCRC) and the Northwest Portland Area Indian Health Board (NPAIHB). Between 2010 and 2012, study participants were identified from the Oregon State Cancer Registry and Northwest Tribal Cancer Coalition member referrals, flyers placed at tribal clinics in Oregon and Washington, cancer survivor support groups, and mailings from the NPAIHB. Cancer survivors were eligible for the study if they (1) identified as AI/AN; (2) had a primary diagnosis of any cancer within 5 years of study recruitment; (3) resided in Washington or Oregon at the time of recruitment; (4) had no prior or subsequent malignancy to the primary cancer; and (5) were over 21 years of age. Eligible participants were excluded if the respondent was unable to communicate or too ill to complete the interview or if their treating physician indicated that participation in the study was inappropriate. To capture the experience of survivors who could not complete an interview, primary caregivers were recruited through the same methods as those described for cancer survivor participants. Caregivers were eligible for the study if, within 5 years of

recruitment, they spent three or more hours per week providing care to an AI/AN person diagnosed with any cancer who resided in Oregon or Washington State at the time of recruitment. All participants who met eligibility criteria agreed to participate.

Questionnaire development and data collection

During the development of the parent AIMS study, the project team facilitated a focus group of community members and health professionals from the Northwest Tribal Cancer Coalition to establish domains to be targeted by an interview instrument. Based on themes from the focus group, the project team developed an interview tool consisting of demographic, quantitative, and qualitative questions designed to elicit participant experiences with cancer care. The instrument was finalized after pilot testing among AI/AN community members for clarity and cultural appropriateness. As qualitative research can illuminate cultural values and social contexts [19, 20] and has been identified as a successful approach for elucidating the needs and realities of native populations [21–24], in this paper, we focus on the qualitative components of the parent study's interview instruments and the domains relevant to satisfaction with care (Table 1).

Seven staff members, all from federally recognized tribes and experienced in qualitative data collection, conducted interviews by phone or in person at a private office in the community. The interviewers discussed confidentiality and the voluntary nature of the study and obtained verbal consent. Based on recommendations from community partners experienced in research conduct with this population, all participants were provided a \$100 money order for their time and participation in the overall AIMS study.

Data analysis

Open-ended questions were audio-recorded and transcribed verbatim. Transcriptions were checked for accuracy and uploaded into Atlas.ti, version 7 (Berlin, Germany). Through an iterative process, two team members independently coded data utilizing an inductive, conventional content analysis approach, in which concepts are identified and themes derived from interview data [25]. The study team discussed interpretations, developed corresponding codes, and grouped codes into categories representative of the identified emergent themes. In-depth content analysis revealed that most participants described overwhelming satisfaction with their treatment. In an attempt to gain insight into experiences of those with less satisfaction who may be representative of AI/ANs who did not participate in an interview, the team identified deviant (negative) cases, that is, cases that did not fit the pattern of other interviews [20]. The analysis of deviant cases helps ensure validity and allows a more in-depth understanding of a phenomenon, in this case, patient satisfaction with care [20, 26]. To ensure accurate interpretation of quotes, the coders discussed ongoing emergent themes and sought feedback from all members of the project team and community members throughout analysis. To ensure that quotes were selected from a range of participants, coders kept participant identification numbers tagged to quotes until publication and established that one participant could not be quoted more than once. To ensure confidentiality of participants, identification numbers were removed for submission.

All study materials were approved by The Fred Hutchinson Cancer Research Center IRB (#7419), Portland Area Indian Health Service IRB (#08-P-11) NPAIHB Resolution 11-04-02.

Results

Study sample

Between November 2011 and April 2013, 71 eligible AI/AN cancer survivors residing in Oregon (79.4 %) and Washington State (20.6 %) were interviewed (Table 2). All but one survivor had completed treatment or were undergoing treatment at the time of the interview. None reported cancer recurrence. Thirteen (21.3 %) were employed and 46 (76.7 %) were living below 250 % of the Federal Poverty Level (FPL). Eleven eligible AI/AN caregivers were interviewed. Four caregivers interviewed had provided care to individuals who were deceased at the time of the study, and the remaining seven had provided care to individuals who were living but unable to complete an interview. Caregivers' descriptions of patient satisfaction largely aligned with those of the survivors interviewed. Six themes emerged regarding how providers facilitated satisfaction with care. Each theme was classified into one of the three categories: (1) universal factors: bolstering understanding, involvement, and empathy in care; (2) minority-specific factors: incorporating culture and community into care; and (3) AI/AN-unique factors: interacting with Indian health clinics and IHS. The themes are described under each of the category headings below.

Universal factors: bolstering understanding, involvement, and empathy in care

Providers offered informational support and built health literacy: Regardless of their initial level of understanding of cancer care, the survivors and caregivers who were satisfied with care said their care providers mitigated this multi-level burden by offering informational support and building health literacy. Providers delivered informational support through multiple means, including conversations during appointments, written materials to read at home, and open invitations to contact the provider should questions arise. Illustrating this theme, a breast cancer survivor recalled:

I went immediately to the specialist, to the surgeon, and they gave me a packet which would give me information regarding my cancer and they said I could go back and call them any time I had any questions on it. But it was pretty well laid out... The person that I spoke to actually did a lot of help for me as far as what to expect.

Even caregivers observed that providers further helped patients understand their treatment by explaining processes in a straightforward language, as illustrated by this caregiver, who said:

The doctors really made a big difference. They worked to break it down into terms that we could understand, and it was really reassuring as far as how the outcome would be, and it just felt he really cared about his patients. It just made us feel better, and he was very confident in how he talked to us, and it just felt really good that he was on our side.

Providers promoted shared decision-making processes and patients' healthcare self-

efficacy: Providers' ability to listen and invite questions, thereby involving respondents as decision-makers in their own treatment, emerged as a key element for satisfaction. The respondents said explanations about their disease and care offered by providers prepared them to be informed, involved participants in decisions regarding their cancer care. A breast cancer survivor reported:

My doctor, he was really good and he showed me three different plans I could follow and gave us great statistics for each plan. And even though we took the more lengthy route, there was a better chance of survival rate than the other routes.

Relatedly, a breast cancer survivor recalled, "Well, I had a really good doctor, [name], who gave me some options and actually told me which would be better for me...so I took him up on the chemo and the radiation."

Providers practiced empathic communication: The survivors and caregivers further widely reported that care providers' empathic communication practices contributed to satisfaction. For example, a colorectal cancer survivor said:

I was very serious about not wanting to go (finish treatment)... People at the hospital were real good, where I went to do the treatment. They must've gone to classes to learn how to be so nice. It's such a painful time. They were always behind me with one hundred percent support.

The survivors and caregivers said providers showed support by demonstrating kindness and care and by acknowledging their struggle. A lung cancer survivor relayed his experience, reporting, "The nurses up there and radiation and the whole crew there were very friendly and, you know, talk to you all the time, you know, and it made you feel like somebody cared." A caregiver reported that "the reassurance of the specialist (who) laid (the treatment plan) out very well and reassured her that she was going to be okay" facilitated the patient's satisfaction.

Minority-specific factors: incorporating culture and community into care

Providers engaged family members and caregivers: Similar to other minority groups with communalistic values, involving family members emerged as an important factor in how care providers increased satisfaction and helped ease the burden for AI/AN patients receiving a diagnosis and progressing through cancer treatment. A colorectal cancer survivor recalled her experience receiving colonoscopy results, in which:

The doctor goes, "Where's your husband?" And I'm looking at him like, oh, it's bad....So my husband comes walking in...and (the doctor) says, "Well, I just want him here when I say this, because I don't want to shock you and having your husband here with you will help."

Additionally, survivors said they were satisfied with care when providers invited dialog with both patients and family members, many of whom served as caregivers. A breast cancer survivor said:

The doctors here in town were just wonderful, and they all said, “If any of your family has questions, just give them our number and what hours we’re in.” My daughter always had more questions than I did, because you get where you can’t think. You know what you wanted to ask. By the time you get there you done forgot it.

Summarizing his family member’s cancer care experience, this caregiver reported, “The family support, the doctors, and information combined just made things more reassuring that what we were doing was right, caught it in time, and everything’s going to be okay.”

Providers demonstrated sensitivity to AI/AN cultural healing traditions: Provider awareness and comfort with AI/AN cultural healing traditions was an important influence on satisfaction. About a third of respondents reported using AI/AN traditional medicines, healers, and tribal knowledge in relation to their cancer diagnosis. Most said they discussed these alternative approaches with their care providers, who offered encouragement and sensitivity about integrating traditional and conventional treatments. For example, a breast cancer survivor said her surgeon embraced her need for ceremony when she “told them I needed my eagle feather hanging from my IV thing, and he asked me what it was for and I says, ‘Well, the eagle feather is my protection. It’s my power, my healing.’ So he understood that.”

Though most respondents who discussed the use of traditional medicine with their care providers were met with support, some participants were either reluctant to share this information with care providers or felt disregarded, such as this survivor who reported:

I tried to (discuss traditional medicine with providers). It was kind of one of those things where they didn’t want to hear it. They didn’t want to discuss it....They didn’t take the things I said seriously. They treated me like I was a complete idiot, and that was really, really difficult.

AI/AN-unique factors: interacting with Tribal health clinics and IHS—Most respondents described satisfaction in the context of universal and minority-specific factors. When explaining unique factors, however, the majority of survivors and caregivers indicated dissatisfactory experiences.

Coordination of care with IHS: The respondents who expressed dissatisfaction often discussed the delays due to conflicting regulations between cancer care providers and primary care providers, as described by this caregiver, “The rules and regulations between, like I said, IHS, (primary care provider), and the oncology...I think her most challenging [experience] was definitely when it came to...trying to realize the rules of each of the programs.”

When asked what made the cancer care experience more difficult, another caregiver explained, “I think the communication between IHS and Contract Health (care provided away from IHS) and the oncology... just having the doctors complete the applicable paperwork in order for her to get the prescription filled [was difficult].”

Declaring AI/AN status: A less common, but historically relevant, factor related to satisfaction was respondents' perceptions about the need to declare one's AI/AN identity. Interestingly, participants who were not perceived as indigenous often described better care but lower satisfaction. One survivor noted:

I had a medical provider change my ethnicity from Native to White, and when that changed, my care got better. But when I found it was changed, I made them put it back, and then the attitudes shifted again. I think there was some negative attitudes and ideas about who and what Native people are.

Another survivor recalled: [No care providers] ever came in and talked or negotiated or mentioned anything about our culture, our background, or who we are...I wish I would have mentioned my Native American [identity]. I think they would have reacted a little differently at the time when I was recovering.

Discussion

In this study, we used community-based, qualitative interviews to identify universal, minority-specific, and culturally unique factors that may influence cancer care satisfaction among AI/AN cancer survivors and caregivers in Oregon and Washington State. We identified issues that have been reported previously for other minority populations, and the unique situation that many AI/AN face when they are diagnosed—specifically that Tribes contract with external health organizations for cancer care—influence both satisfaction with care and possibly care itself.

Survivors' and caregivers' access to informational support and shared decision-making resulted in improved satisfaction with care. Our findings support those of other studies which have found that improved understanding of disease complexity, treatment options, and collaboration enhance satisfaction and are relevant across race/ethnicity and socioeconomic status [8, 11]. The role of empathic communication and trust between providers and patients, particularly among minority groups, for promoting satisfaction and treatment adherence is also well-documented [9, 12, 13, 27]. The current structure of the IHS and Contract Health as described above may contribute to the challenges in communication experienced by participants in this study. Increased efforts to coordinate care are needed.

Previous studies have highlighted the importance of cultural competency and cultural congruence in delivery and satisfaction with health care [8, 28]. Our study adds to the literature the culture-specific needs of AI/AN cancer survivors receiving specialty care. The participants in this study described culturally competent providers as those who were able to inquire about cultural specific needs and support survivors in integrating traditional medicines and tribal knowledge into their cancer care. These providers also recognized the value and need to engage family members and caregivers throughout treatment.

A major theme emerging from this study was the importance of involving AI/AN patients' family members in their cancer care. Shared decision-making, a model in which patients are actively engaged by providers in their treatment decisions, has been proposed as an approach to enhance patient satisfaction, treatment outcomes, self-rated improvement, and

psychological well-being [29]. Our findings further suggest that successful shared decision-making approaches for AI/AN patients must involve patients as well as their larger support networks of family members and caregivers. This approach aligns with AI/AN cultural values of preservation, continuity, and community [17, 21]. Indeed, shared decision-making models that integrate cultural case management may be exceptionally well-suited to address disparities in AI/AN populations, given the diversity of AI/AN cultural values and varying degrees of cultural assimilation [30–35]. Future work is thus needed to evaluate whether team-based approaches to shared decision-making interventions and case management in primary care are relevant to specialty care settings where AI/ANs receive cancer treatment and follow-up care.

AI/ANs face culture-unique systemic barriers such as health resource shortages within IHS and continuity of care problems between IHS and specialty care services [2, 18]. Specialty care services, including cancer care, are not directly available through tribal clinics. Instead, specialty care is referred through Contract Health Services, which requires AI/AN patients to undergo cumbersome application processes and still not be guaranteed care [36]. Not surprisingly, many participants cited challenges with transitioning between primary care—provided within IHS—and specialty care provided through Contract Health. Although the Affordable Care Act has reinstated the Indian Health Care Improvement Act that may address some of these challenges, studies have not yet been conducted to determine the impact of the healthcare reform provisions on improved coordination between IHS and Contract Health. More research is needed to investigate the challenges, gaps in care, and inter-disciplinary communication and identify strategies for easing transitions between primary care and specialty cancer care.

This study has several limitations. Our study was based on interviews conducted with AI/AN cancer survivors and caregivers, and all but one had completed treatment at the time of interview. Thus, the participants may have exhibited survivorship bias or reported disproportionate satisfaction. Those who were dissatisfied may have been unlikely to participate in the Support Care Cancer study or are deceased. We tried to account for these participants by interviewing caregivers, in cases in which patients were unable to complete the interview. Similar themes emerged for both survivors and caregivers in this study, and the number of caregiver interviews was limited. Future studies may benefit from seeking perspectives of a wider sample of caregivers to better understand the needs of patients' support system during care. Finally, our study describes just one modifiable factor that may influence satisfaction with care, and subsequent cancer treatment initiation and adherence among AI/ANs. Yet, other multi-level factors also play a role, particularly with regard to AI/ANs ability to access healthcare services. For example, issues such as socioeconomic status, transport and distance from care facilities, Indian Health Service access and infrastructure, and social support may limit AI/AN patients' care-seeking behaviors and serve as barriers to receiving timely and appropriate care [7, 8, 18, 37, 38].

Conclusion

As treatment models increasingly emphasize patient-centered care, providers, communities, and health systems have a unique opportunity to develop and implement integrated

approaches that can more effectively address satisfaction of cancer care among AI/ANs. This paper is among the first to qualitatively explore dimensions of cancer care satisfaction among AI/AN cancer survivors and caregivers. Previous studies have focused on satisfaction among the general population or other minority groups or have used a quantitative approach that may not illuminate influences on satisfaction that are minority-specific or AI/AN-unique [16]. The results of our study suggest that satisfaction with care among survivors and their caregivers must be examined within the context of culture and community, particularly among minority patients. Empathic communication and shared decision-making represent universal needs regarding satisfaction with care across diverse racial/ethnic groups. Additionally, shared needs exist among the members of minority groups, such as family/community engagement and cultural sensitivity. Our study demonstrates providers' critical role in ensuring AI/AN patients emerge satisfied with cancer treatment by honoring their AI/AN-specific needs, such as respect for integration of traditional healing modalities and navigation of specialty care coordination. Our study also highlights the need for future research that addresses systemic challenges in coordinating primary care through the IHS and specialty care for AI/ANs. Enhancing providers' abilities and tools to deliver clear information, demonstrate cultural competence, and assist survivors in navigating specialty care may increase the number of AI/ ANs who complete cancer care once diagnosed.

Acknowledgments

The authors would like to thank the staff and investigators at all collaborating institutions: the FHCRC Hutchinson Institute for Cancer Outcomes Research (HICOR); the Northwest Portland Area Indian Health Board; and the AIMS Advisory Board, Oregon State Cancer Registry. We would also like to extend our gratitude to the study participants and community members, who provided insight and perspective, and without whom this work would not be possible.

Funding This work was supported by grants from the National Institutes of Health (NIH), National Cancer Institute (NCI) (R01CA125231 to S. Ramsey).

Abbreviation

AI/AN	American Indian/Alaska Native
AIMS	Cancer among American Indians: A Multi-State Study
FHCRC	Fred Hutchinson Cancer Research Center
HICOR	Hutchinson Center for Cancer Outcomes Research
IHS	Indian Health Service
NHW	non-Hispanic whites
NPAIHB	Northwest Portland Area Indian Health Board

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Table 1

Example domains and interview questions

Domain relevant to satisfaction with care	Example interview question ^a
Referral process	What happened with your care during the time between your diagnosis and starting treatment?
Treatment decision-making	During the time you were deciding to have cancer treatment, what made this process easier? What made the process more difficult?
Treatment options	Were you presented with different treatment options?
Traditional medicine	Did you use any traditional Indian medicine, healers, or tribal knowledge in your treatment? What was it like to discuss this with your cancer doctor?

^a Interviewers were trained to ask follow-up probes relevant to individual participant responses

Table 2Survivor characteristics ($n=71$)

Characteristic	Number	Percent
Gender		
Female	49	(69.0)
Employment		
Employed	13	(21.3)
Not employed	22	(36.10)
Retired	26	(42.6)
Income		
<FPL250 %	46	(76.7)
>FPL250 %	14	(23.3)
Marital status		
Married/living with partner	31	(43.7)
Divorced/widowed/separated	27	(38.6)
Other	12	(16.2)
Education		
<High school	8	(12.9)
High school graduation (or GED certificate)	36	(58.1)
College graduate or higher	18	(29.0)
State of residence		
Washington	14	(20.6)
Oregon	54	(79.41)
Living on reservation	13	(18.3)
Cancer diagnosis		
Breast	33	(46.5)
Colorectal	11	(15.5)
Prostate	10	(14.1)
Lung	5	(7.0)
Other	12	(16.9)

GED General Education Development