Understanding American Indian Perceptions Toward Radiation Therapy

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Abstract

Many American Indian (AI) and Alaska native (AN) patients do not complete guideline-concordant cancer care for the 4 most common cancers. Our aim was to better understand AI/AN attitudes toward radiation therapy (RT). Patients eligible for this survey study were AI/AN patients with cancer at the Phoenix Indian Medical Center who either received previous RT or were recommended to receive RT. An I8-item questionnaire was administered to each of the 50 participants from October I, 2018, through February I5, 2019. Willingness to travel for RT was compared to respondent characteristics, concerns regarding RT, and obstacles to obtain RT. Duration of RT was important to 78% of patients: 24% would consider traveling 25 miles or more for a standard course, and 48% would travel that distance for a shorter course (P < .001). The top-ranked barriers to RT were transportation, cost of treatment, and insurance compatibility. The top-ranked concerns about RT were adverse effects, cost of treatment, and fear of RT. Concerns about adverse effects were associated with the radiation team's inability to explain the treatment (P = .05). Transportation concerns were significantly associated with accessibility (P = .02), communication with the RT team (P = .02), and fear of RT (P = .04). Al/AN patients are concerned about the adverse effects of RT and the logistics of treatment, particularly costs, transportation, and insurance compatibility. Use of culturally specific education and hypofractionation regimens may increase acceptance of RT for Al/AN patients with cancer, and this hypothesis will be tested in a future educational intervention-based study.

Keywords

adverse events, American Indian, cost, insurance, radiation therapy, transportation

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Introduction

In 2018, 6.8 million people identified as American Indian (AI) or Alaska native (AN). The AI/AN group is a particularly vulnerable section of the US population with a long history of lower health status, the lowest life expectancy of any racial group (6.4-8 years less than whites), and an exceptionally high incidence of diabetes mellitus, chronic liver disease, accidents, and suicides. Life expectancy of AI/AN has decreased further: The premature death rate increased in most AI/AN age groups between 1999 and 2004, while it decreased in all Hispanic, black, Asian, and Pacific Islander populations (rates for white Americans were variable).

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Many socioeconomic disadvantages and behavioral risk factors coincide with these health disparities. Compared to the general population, AI/AN populations have lower educational attainment, higher disability rates, lower rates of employment and health insurance coverage, and more than twice as many families living in poverty. AI/AN populations also have significantly higher levels of tobacco use and alcohol use disorder, and AI/ANs are less likely to exercise. 5-7

Cancer was the second leading cause of death in AI/AN populations and in the United States as a whole in 2016,⁸ but only AI/ANs showed an increase in overall cancer incidence in recent trends.⁹ AI/AN communities have lower rates of cancer screening,^{7,10-12} and AI/ANs are less likely to undergo guideline-concordant cancer treatments, such as radiation therapy, when cancer is diagnosed.^{13,14} Consequently, they disproportionately present with advanced-stage cancers, they underuse hospice care, and they are more likely to die of their cancers than non-Hispanic whites.^{13,15-17}

Clinical nonadherence in AI/AN populations results from inadequate education about cancer, geographic remoteness, mistrust of health care providers, discrimination, and dissatisfaction with the decision-making process. 10,11,18-22 Culturally tailored programs (eg, the "Walking Forward" program^{23,24}) have demonstrated that improving cultural competency in cancer care with the incorporation of patient navigators can lead to more trusting partnerships, improve the use of cancer screenings, and increase patient adherence to radiation therapy regimens. 18,20,23,25 This program is promising, but to our knowledge, AI/AN-dedicated health equity initiatives continue to be limited in number and scope, and the data in this area are sparse. Particularly, information about AI/AN perceptions of radiation therapy is inadequate, and it is important to understand whether there are any unique perceptions. Our aim was to further investigate AI/AN attitudes toward radiation therapy to identify relevant venues for change for the future.

Methods

Sample and Data Collection

The quantitative survey for this study was designed to help better understand perceptions and attitudes of AI/AN patients with cancer toward radiation therapy. Fifty adult AI/AN patients at the Phoenix Indian Medical Center (PIMC) were recruited to complete the paper-and-pencil survey from October 1, 2018, through February 15, 2019. Because the study was a small pilot and feasibility study, the sample was a targeted, convenience sample of 50 AI/AN patients with cancer who had undergone, were undergoing, or were referred to undergo radiation therapy. All eligible patients with cancer received radiation therapy in their regimen as determined by their oncology team according to standard of care for the diagnosis. Eligible patients with appointments at the medical center were identified and referred to speak with study staff to determine their interest in participating in the study.

Written informed consent was required and provided by all participants. All disclosure statements, consent forms, and study materials were in lay language and were provided in English, including information about the study and the potential risks and benefits of participation. The study and all study materials were approved by the medical center institutional review boards.

All data were collected by trained study staff who were onsite weekly until data collection was completed. To be eligible for participation, all participants had to speak and read English well enough to clearly understand and give informed consent and to complete the paper-and-pencil survey. If they needed help understanding survey items, participants could request assistance from the data collector. The survey took about 10 to 20 minutes to complete.

Measures

The paper-and-pencil survey included 18 questions for assessing perceptions and attitudes toward radiation therapy. Measures included basic demographic information, such as age, gender, employment, living situation, cancer diagnosis, and the distance participants currently travel and might be willing to travel for overall cancer treatment and radiation therapy. Respondents were also asked to rank the biggest barriers to receiving radiation therapy (eg, transportation, cost of treatment, and lack of trust) and the biggest concerns about their radiation therapy (eg, side effects, insurance, cost, religious or cultural beliefs, and fear). The survey also assessed whether the duration of radiation treatment was a barrier.

The Agency for Healthcare Research and Quality Consumer Assessment of Healthcare Providers and Systems Cancer Care Survey, Radiation Therapy Survey, ²⁶ was the source for 3 items that asked respondents about their interactions with their radiation therapy team. Specifically, these 3 items assessed the communication between the radiation therapy team and the patient.

Data Analysis

Survey and sociodemographic data were collected. The Fisher exact test and the Wilcoxon rank-sum test were used to assess associations between current and future willingness to travel for radiation therapy and respondent characteristics, barriers to radiation therapy, and concerns about radiation therapy. Prognostic factors for willingness to travel were modeled univariately with logistic regression and summarized as odds ratios (ORs) and 95% CIs. Multivariate logistic regression was considered for all univariately statistically significant (P < .05) variables through a stepwise selection procedure. All statistical analysis was conducted with SAS version 9.4 (SAS Institute Inc).

Results

Patient characteristics are summarized in Table 1. More than half the survey respondents (54%) were younger than 60 years.

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With the majority of patients being women (84%), the most common type of cancer identified was breast cancer (62%). The "Other" category included sarcomas, lung cancer, nasopharyngeal carcinoma, Merkel cell carcinoma, and unspecified types. A minority of patients lived alone (12%), and 38% of patients were currently employed.

One survey question asked, "How often did your radiation therapy team explain things in a way that was easy to understand?" The response from 68% of patients was "Always," 12% responded "Usually," and 12% responded "Never" or "Sometimes." Another question asked, "How often did your

Table 1. Patient Characteristics From Brief Radiation Therapy Survey.^a

	Pati	Patients	
Characteristics	n	%	
Age, years ^b			
≥60	23	46	
≥65	13	26	
≥70	7	14	
Gender			
Female	42	84	
Male	8	16	
Cancer type			
Breast	31	62	
Testicular	2	4	
Skin	2	4	
Renal	2	4	
Rectal	3	6	
Prostate	2	4	
Other ^c	8	16	
Lives alone	6	12	
Currently employed	19	38	
Received radiation therapy	44	88	

 $^{^{}a}N = 50.$

radiation therapy team listen carefully to you?" The response from 70% of patients was "Always," 12% responded "Usually," and 10% responded "Never" or "Sometimes." There was a significant correlation between patients who responded to both questions in the same manner (P < .001).

Figure 1 summarizes survey responses about traveling for radiation therapy. Almost all (90%) patients traveled less than 50 miles for their radiation therapy. When asked about the maximum distance they would consider traveling for radiation therapy, the majority (76%) replied that they would travel less than 25 miles, and 10% would travel more than 75 miles. The duration of radiation therapy was important to 78% of patients: 24% would consider traveling 25 miles or more for a standard course of radiation therapy, and 48% would travel that distance for a shorter course of radiation therapy (P < .001). Moreover, when given the option for a shorter course of radiation therapy, nearly 4 times as many patients who were currently employed, compared to unemployed patients, would travel more than 50 miles for radiation therapy (P < .001).

Table 2 summarizes barriers and concerns related to radiation therapy. The barriers to radiation therapy that were most often ranked as most important were money/cost of treatment, transportation, and insurance compatibility. The concerns about radiation therapy that were most often ranked most important were adverse effects, money/cost of treatment, and fear of radiation therapy. Subgroup analysis showed that concern about adverse effects was associated with fear of radiation therapy and communication with providers about treatment (P = .05). Concern about transportation was significantly associated with accessibility (P = .02), communication with providers about treatment (P = .02), and fear of radiation therapy (P = .04).

Discussion

To our knowledge, AI/AN perceptions of radiation therapy have not been reported previously. For AI/AN patients surveyed at the PIMC, several concerns and barriers were important when they considered undergoing radiation therapy.

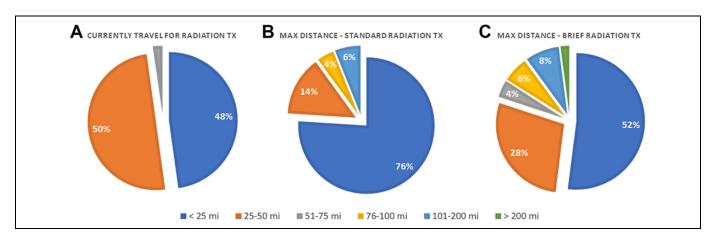


Figure 1. Travel distances to receive radiation therapy (TX). A, Distance traveled by patients currently. B, Maximum (MAX) distance that patients would be willing to travel to receive standard radiation TX. C, MAX distance that patients would be willing to travel to receive hypo fractionated radiation TX.

^bMean (SD) age, 58.1 (11.7) years; range, 27 to 85 years.

^cSarcomas, lung cancer, nasopharyngeal carcinoma, Merkel cell carcinoma, and unspecified types of cancer.

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Table 2. Barriers to Radiation Treatment and Concerns About Radiation Therapy.

Item	Mean (SD) Rank	Top Ranked, %ª	Range
Barriers			
Transportation	2.5 (1.7)	26	1-6
Lack of trust in the medical system	4.7 (1.8)	4	1-9
Insurance compatibility	2.6 (1.6)	8	1-8
Money/cost of treatment	2.4 (2.0)	28	1-8
Communication with providers about treatment	4.0 (1.6)	0	2-7
Accessibility of the medical facilities	3.4 (1.8)	6	0-6
Concerns			
Adverse effects	1.9 (1.5)	38	1-7
Transportation	3.7 (2.0)	4	1-8
Insurance	3.7 (2.2)	4	1-8
Money/cost of treatment	2.9 (2.3)	18	1-8
Communication with providers about treatment	4.4 (1.9)	6	1-8
Accessibility of the medical facilities	4.6 (2.1)	2	1-7
Religious/cultural beliefs	6.6 (2.1)	2	1-8
Fear of radiation therapy	3.8 (2.5)	14	1-9

^aPercentage of patients who ranked the item as most important.

However, the fact that a prospective survey study was successfully conducted at an Indian Health Service medical center showed that continued progress is possible in establishing trust with the AI/AN community.

Distrust of researchers by the AI/AN population is well documented.²⁷ In the past, government policies designed to decimate the AI/AN population led to unethical research protocols. One example from the 1970s is the sterilization of AI women without informed consent.²⁷ The reasons that AI/AN persons lack interest in research studies include the following: (1) They do not want to be guinea pigs, (2) study findings are rarely shared with the participating communities, (3) study findings are rarely acted upon to improve services for the community, (4) promised benefits of the study rarely reach the AI community, and (5) access to resources to participate in the study is insufficient.²⁸

Both medical centers developed a clinical oncology practice collaboration that has been active since 2008. ²⁹ By embedding oncologists from the Mayo Clinic within the oncology clinic at the PIMC, a valuable service could be provided to the AI/AN community. From 2008 through 2017, a total of 356 patients with breast cancer and 259 with colorectal cancer were seen in addition to patients with other cancers and blood disorders. ²⁹ With no prior clinical trial referrals before the established partnership, 13 clinical trial referrals occurred over a 1-year span. This successful partnership provided a trusting framework to conduct our survey study at the PIMC. Another example of successful collaboration is the Walking Forward program between the western South Dakota AI population and the Regional Health Cancer Care Institute in Rapid City, South

Dakota. ^{23,24} This program has provided cancer screening education and care to more than 1900 AIs.

In our study, patients highly ranked their concern about the side effects of radiation therapy. Radiation therapy is unfamiliar to many patients, and a large proportion of the oncology care team's time is spent educating patients about the radiation treatment process and demystifying it for them. Existing radiation oncology educational materials are meant for the general public and lack cultural sensitivity, particularly for the AI/AN population. Therefore, we hypothesize that an opportunity exists to develop more culturally sensitive materials about radiation therapy for the AI/AN population. Our next phase of study is a randomized study to examine educational materials that are more culturally sensitive than the current standard materials and to determine whether the culturally sensitive materials alleviate AI/AN concerns and barriers related to radiation therapy.

Preliminary interviews with patient education representatives at the PIMC indicated a desire for graphically oriented written materials focusing on the patient journey. Through iterative interviews with the patient education team at the PIMC and with patient volunteers at the PIMC, we plan to construct a graphically oriented educational narrative regarding a patient's journey through radiation therapy. As noted, the educational material will be tested in a randomized fashion with validated patient questionnaires such as the European Organization for Research and Treatment of Cancer Quality of Life Group information questionnaire (EORTC QLQ-INFO25), which was specifically designed to assess the information given to patients.³⁰

The logistics of radiation therapy continue to be a barrier for AI patients, with the majority noting that duration of radiation therapy is important. Difficulties arise from the geographic remoteness of many AI/AN reservations and related transportation details coupled with the duration of radiation therapy, which can involve more than 30 fractions for many curative situations. The field of radiation oncology is moving toward the use of more hypofractionated regimens, which should help to minimize patients' transportation burdens. One example is the treatment of breast cancer, in which the new standard of care is hypofractionated regimens delivering radiation therapy over 3 weeks. ³¹ Our survey results showed that for shorter treatment regimens, patients were willing to travel farther for radiation therapy.

Survey-based research has limitations, including oversimplification of social reality and the validity and reliability of results. One fair criticism of this study is that some or all of the results reported may not be unique to the AI/AN population. Fear of radiation therapy could be attributed to a more general population. A larger survey study of patients with breast cancer reported that 68% of respondents had little or no prior knowledge of radiation therapy, with almost half the patients reporting that they had heard or read frightening stories of serious adverse events with radiation therapy.³² That study, however, did not include the AI/AN population; therefore, our study supplements the literature and shows that AI/AN perceptions

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are consistent with those of other racial and ethnic groups. This raises the question of whether all racial and ethnic groups would benefit from culturally specific education. Efforts to understand the difference between equality and equity and to focus educational efforts on groups with poorer cancer outcomes, such as the AI/AN population, could increase the willingness of patients to pursue radiation therapy, which could lead to better adherence to guideline-concordant care.

This hypothesis-generating study is leading to a randomized study that uses educational material developed in conjunction with the PIMC and patient feedback. We plan to study the impact on patient anxiety, patient satisfaction with the education provided, and radiation therapy completion rates.

Conclusion

American Indian/Alaska native patients are concerned about the adverse effects of radiation therapy. The logistics of treatment, particularly costs, transportation, and insurance compatibility, are barriers. The use of culturally appropriate education and hypofractionation regimens may increase acceptance of radiation therapy for AI/AN patients with cancer. Testing of this hypothesis will be performed with a prospective study based on an education intervention.

Authors' Note

The views expressed are those of the authors and do not necessarily reflect those of the Indian Health Service. Ms ID CCX-20-0142. Written consent was obtained from the patients before the survey was conducted. Before research was begun, the investigation was approved by the medical center IRBs. Written consent was obtained from the patients before the survey was conducted.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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