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## Patient navigation for American Indians undergoing cancer treatment: utilization and impact on care delivery in a regional health care center

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### Abstract

**Purpose**—To assess patient navigation (PN) utilization and its impact on treatment interruptions and clinical trial enrollment among American Indian (AI) cancer patients.

**Methods**—Between February 2004 and September 2009, 332 AI cancer patients received PN services throughout cancer treatment. The PN program provided culturally-competent navigators to assist patients with navigating cancer therapy, obtaining medications, insurance issues, communicating with medical providers, and travel and lodging logistics. Data on utilization and trial enrollment were prospectively collected. Data for a historical control group of 70 AI patients who did not receive PN services were used to compare treatment interruptions among those undergoing PN during curative radiation therapy (subgroup of 123 patients).

**Results**—The median number of contacts with a navigator was 12 (range, 1-119). The median time spent with the navigator at first contact was 40 minutes (range 10-250 min.) and 15 min for subsequent contacts. Patients treated with radiation therapy with curative intent who underwent PN had fewer days of treatment interruption (mean, 1.7 days; 95% CI, 1.1-2.2 days) than historical controls who did not receive PN services (mean, 4.9 days; 95% CI, 2.9-6.9 days). Of the 332 patients, 72 (22%; 95% CI, 17-26%) were enrolled on a clinical treatment trial or cancer control protocol.

**Conclusions**—PN was associated with fewer treatment interruptions and relatively high rates of clinical trial enrollment among AI cancer patients compared to national reports.

### INTRODUCTION

It is well-established that cancer-related health disparities exist with respect to race/ethnicity and socioeconomic status, 1-5 and American Indians (AI) in the Northern Plains region of the US exhibit some of the highest cancer mortality rates in the nation. 6-7 Investigators have demonstrated that reasons underpinning health disparities among vulnerable

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populations are multi-factorial. 2<sup>7</sup> 8<sup>9</sup> Studies have shown lower rates of screening utilization among AIs, 6<sup>10</sup> 12 as well as higher rates of presenting to medical care with advanced stages of cancer at diagnosis for AIs in this region. 13 In addition, AI cancer patients in the Northern Plains, where some of the largest reservation-base AI communities are located, demonstrate lack of trust of health care providers and hospitals,<sup>14</sup> and negative attitudes about cancer treatment.<sup>15</sup> American Indians in the Northern Plains reside in some of the poorest census tracts in the US, with almost half of individuals living below the federal poverty level and the unemployment rate at approximately 80% on some reservations.<sup>16</sup> Furthermore, the Indian Health Service (I.H.S.) which provides health services to enrolled tribal members has been chronically under-funded thus hobbling a primary source of health care delivery for this vulnerable population. 17<sup>19</sup>

As the field of health disparities research evolves from one of defining the extent and causes of disparate health outcomes to solutions to health inequities, patient navigation (PN) has emerged as a potential strategy to mitigate access barriers in targeted populations. The early model for cancer PN, established by Freeman and colleagues in Harlem, New York in the early 1990's,<sup>20</sup> 21 showed improved 5-yr survival (from 39% to 70%) for breast cancer patients in a low-income inner city population. Since that time multiple investigators have shown improvement in cancer-related health outcomes after implementation of PN services among various populations. 22<sup>28</sup> Most cancer PN studies have focused on increasing screening rates among minority populations or decreasing the time intervals between the various critical points in early cancer management such as that between detection of a screening test abnormality through diagnosis and initiation of cancer treatment. 24<sup>27</sup> 29 Relatively few studies provide data on PN during cancer treatment itself.<sup>30</sup> Data are needed on the intensity and nature of PN utilization during cancer treatment, and the impact of navigation on treatment-related outcomes. For example, treatment adherence may be improved by PN. This possibility is especially relevant for patients undergoing curative irradiation, a situation where treatment interruptions have been shown to impact survival and recurrence outcomes. 31<sup>33</sup> Another potential benefit of PN may be the ability to boost clinical trial enrollment among minority populations, through the presence of a culturally competent navigator to help establish trust and assist in identifying eligible patients which have typically been underrepresented in clinical trial participation.<sup>34</sup> 35

In 2003, a review of the Rapid City Regional Hospital's (Rapid City, South Dakota) tumor registry (from 1990-2003) revealed that AI cancer patients presented with disproportionately high rates of advanced-stage malignancy.<sup>13</sup> 36 Subsequent to these findings a culturally-tailored PN program was implemented to assist AI cancer patients through the cancer care continuum from diagnosis through follow-up after cancer treatment completion. The purpose of this study is to report upon patient navigation utilization during cancer treatment and to evaluate potential impacts on clinical care.

## METHODS

### Study population

Between January 2004 and September 2009, 375 AI cancer patients presented to Rapid City Regional Hospital (RCRH) Cancer Care Institute (CCI) in Rapid City, South Dakota and were approached and offered the services of a culturally competent patient navigator. Of those, 43 patients (11%) refused patient navigation for the following reasons: 39 felt that PN was not necessary; 2 patients did not trust a patient navigator to be involved in their care; and 2 patients did not specify a reason. The remaining 332 AI cancer patients were enrolled on a PN protocol for PN throughout cancer treatment. Patients were identified and enrolled on the protocol at first visit to CCI if at all possible or as soon as possible if eligibility capture was not established at first visit. Race was self-identified by the patient.

All AI patients presenting to RCRH with a diagnosis of malignancy were eligible to participate. Rapid City Regional Hospital serves as the major secondary and tertiary cancer care provider for more than 70,000 adult AIs in the region which includes the Oglala Sioux Tribe (Pine Ridge), Cheyenne River Sioux Tribe, Rosebud Sioux Tribe, and the Rapid City AI population. All AI patients in this study reside in one of these communities, but eligibility for participation was not restricted to specific tribal affiliation. The RCRH's Investigation Review Board (IRB) granted approval to conduct the PN intervention and study. In addition, the protocol was also approved by the following entities prior to initiation: the IRB of the Aberdeen Area Indian Health Service (IHS), Aberdeen Area IHS Tribal Chairman's Health Board, Tribal Councils and Health Departments (Cheyenne River Sioux Tribe, Oglala Sioux Tribe, Rosebud Sioux Tribe), and IHS Hospital Chief Executive Officers (Cheyenne River IHS Hospital, Pine Ridge (Oglala) IHS Hospital, Rapid City Sioux San IHS Hospital, and Rosebud IHS Hospital).

### **Patient navigation program**

In 2003, RCRH was awarded a Cancer Disparities Research Partnership (CDRP) grant to study cancer-related disparities previously documented in this vulnerable population<sup>6-7, 13</sup> and to increase clinical trial availability and enrollment in this medically underserved region.<sup>37</sup> Since that time a multifaceted, community-based participatory research and intervention effort, called the Walking Forward Program,<sup>13, 36, 38, 39</sup> has been developed to explore root causes of disparities, increase cancer screening and education, enroll patients on and educate them about clinical trials, and to provide comprehensive, culturally-tailored PN throughout cancer treatment. Through this effort, AI cancer patients were offered PN services whereby patients were assisted in navigating the medical system by trained, culturally-competent staff to serve as advocates through the cancer care continuum after cancer diagnosis. The patient navigators assist with coordinating appointments, insurance issues, following up on tests, obtaining medications and specialty services or devices, facilitating transportation and lodging, and offer psycho-social support during treatment. In addition to the hospital-based navigators, the navigation program also includes community research representatives (CRR) who work closely with the hospital staff and are embedded in the surrounding AI communities provide cancer education, network with local health resources, and serve as liaisons between the cancer center, hospital-based patient navigators, and patients or tribal governments. Patient education materials were translated into the Lakota language. The cancer center staff members involved in this effort were either closely connected with or are members of the American Indian communities served by this program. More details regarding the development of this PN program have been described elsewhere in the literature.<sup>39, 40</sup>

### **Utilization data collection and statistical analysis**

We prospectively collected data regarding needs addressed and services rendered for each contact with the patient navigator. The navigator completed a contact sheet at each interaction with a patient whether it was by phone or in person. The barriers that were addressed and time spent with the patient were recorded for each contact. Data were tracked as patients moved through the cancer care continuum from diagnosis (if it occurred at CCI) and evaluation through follow-up/surveillance after treatment completion. Contact with the navigator occurred either in person, on the telephone (except for the initial contact, which was always in person), or in some cases the navigator went to homes or hotel rooms of patients to offer assistance when patients were too sick to come to CCI for scheduled treatments. In addition, patient demographics, cancer site, stage and treatment information were abstracted from the medical record or obtained at enrollment interviews. Data were de-identified, and all analyses were performed using SPSS version 17.0 statistical software (Apache Software Foundation). Analysis of variance was performed to test for difference

between means. Confidence intervals (CI) were calculated for proportions and means where appropriate and used along with proportions and means to describe general characteristics.

### Analysis of treatment interruptions

We performed an analysis of radiation treatment (RT) delays for patients treated with RT with curative intent. Those treated with curative intent were the focus of this analysis because data exists that shows RT treatment delays can result in compromise of cancer control and survival outcomes for some cancers that are curable at presentation.<sup>31-33</sup> Details of cancer treatment were compiled by a review of the radiation therapy records and hospital chart. Complete data regarding chemotherapy details and interruptions were not available to our staff members who are housed in the department of radiation oncology; therefore, analyses regarding chemotherapy interruptions were not performed as part of this study. For the purposes of comparison, 72 consecutive AI patients treated with RT with curative intent at CCI between April 1991 and April 2004 and who did not undergo PN during treatment were identified to serve as a control group for comparison of days of RT treatment interruptions. Two patients did not complete RT and their data were not analyzed. For the remaining 70 patients (68 treated prior to the availability of PN services and 2 who refused PN services early in the program's existence), RT charts were retrospectively reviewed to ascertain how many days of treatment delay occurred as well as whether the treatment delay was due to machine maintenance or repair versus other reasons (e.g., weather or patient cancelled for other reasons). Delays due to RT machine maintenance or repair was not considered a day of treatment delay.

### Clinical trial availability

Rapid City Cancer Care Institute has primary membership and access to clinical trials through the North Central Cancer Treatment Group (NCCTG). The center also has clinical trial access as an affiliate of the Radiation Therapy Oncology Group (RTOG), Eastern Cooperative Oncology Group (ECOG), National Surgical Adjuvant Breast and Bowel Project (NSABP), Gynecologic Oncology Group (GOG) and Cancer Therapy Evaluation Program (CTEP). In addition, cancer treatment trials were written for prostate and breast cancer under the auspices of the CDRP grant program. During the time of the study approximately 75 cancer-related clinical trials were open. Clinical trial enrollment data were prospectively tracked for all navigated patients.

## RESULTS

### Patient and cancer-specific characteristics for the study population

Table 1 shows patient characteristics among navigated patients. The largest percentage of patients resides on the Pine Ridge (Oglala Sioux) reservation which is located approximately 100 miles from Rapid City (over 2 hours by car if no inclement weather). The median distance lived from CCI (one way) for all patients was 121 miles (range, 10-444 miles), and it should be noted that road conditions on the reservations are such that travel is slower than that possible on average U.S. highways, even in the absence of inclement weather. The primary payer source for medical bills was Medicare for a third of patients and the next most common primary payer was the Indian Health Service in 25% of patients. Very few patients did not speak English (2%), but 36% of patients did speak the Lakota language.

The majority of patients, 205 (62%), underwent cancer treatment with curative intent, and 112 (34%) underwent palliative treatment, corresponding to the similar percentage of patients who presented with stage IV disease (37%). The remaining 15 (5%) did not have their treatment intent established before discontinuing care at CCI (e.g., underwent only consultation or one visit at CCI but sought PN services at the time of that consult.) At the

time of this analysis 113 (34%) patients had died, 76 (67%) of whom were Stage III or IV at diagnosis.

### Patient navigation utilization

Patients were most commonly referred or recruited to the PN program by a CRR or PN program staff member within the hospital (119 patients, 36%); or by their treating physician or oncology nurse (89 patients, 27%). The remaining 124 (37%) patients sought PN through self-referral or referral by someone other than hospital or grant program staff. All 332 patients had at least one visit with a patient navigator and the median time spent with the navigator at initial contact was 40 minutes (range, 10-250 minutes; mean 45 minutes; mode 60 minutes). The median number of contacts with a navigator per patient was 12 (range, 1-119 contacts.) The mode number of contacts was one contact, with 39 patients (12%) having only one contact with a PN. The median time spent with the navigator for subsequent contacts with a navigator after the initial visit was 15 minutes.

For the initial PN contact, the majority of patients were referred to PN for financial assistance (54%) or logistical support, e.g. travel and lodging help (35%). Other reasons included (> 1 reason possible): psycho-social support (35%), care coordination (22%), advocacy (20%), or education (20%). Figure 1 illustrates the reasons for accessing PN services for subsequent visits through the first five contacts with a PN. Generally, a decreasing proportion of patients accessed a PN for help with case management or care coordination after the first visit, but requests for help with financial assistance increased after the first visit. Requests for psycho-social support also increased over the first five contacts with the PN. A higher proportion of patients requested help with advocacy or cancer care education during the first contact with the PN than at subsequent visits through the first five contacts.

Table 2 shows cancer and treatment related characteristics of the study population. Patients undergoing RT had more contacts with a navigator than those not receiving RT (mean, 25 vs. 13 contacts, respectively;  $p=0.0001$ ), as did those receiving chemotherapy vs. those who did not (mean, 24 vs. 15 contacts, respectively;  $p=0.001$ ). Patients who received both chemotherapy and RT also had more encounters with a navigator than those not receiving both modalities (mean, 30 vs. 16 contacts, respectively;  $p=0.0001$ ). Patients undergoing curative treatment had an average of 21 contacts with a navigator compared to 17 contacts for patients receiving palliative treatment ( $p=0.02$ ).

### Treatment interruptions

For the historical control group of 70 AI pts treated curatively but who did not receive PN during their treatment, the average number of treatment days missed was 4.9 days, 95% CI 2.9-6.9 (range, 0-43 days). Of the 332 navigated patients, 188 received RT at CCI. Of these, 129 were treated with curative intent, 59 were treated with palliative intent. Of the 129 pts undergoing RT with curative intent, 6 did not complete their radiation treatment course. For the remaining 123 patients treated with curative RT, mean number of days of treatment delay=1.7, 95% CI 1.1-2.2 (range, 0-20). The mean number of days missed for the two groups was statistically significant ( $p=0.0001$ ) (Table 3). There was no significant difference in the proportion of patients who did not complete treatment ( $p > 0.05$ ). The proportion of days missed in each group due to weather was not significantly different (4% for the control group and 5% for the navigated group,  $p>0.05$ )

### Clinical trial and protocol enrollment

Among the 332 patients enrolled on the patient navigator protocol, 72 (22%; 95% CI 17-26%) were enrolled on a clinical treatment trial or cancer control protocol. Specifically,

50 patients participated in a molecular genetic study for presence of ataxia-telangiectasia mutation (ATM); 17 were enrolled clinical treatment trial (10 of these were enrolled on a cooperative group trial); and 5 patients were enrolled on both the ATM study and a clinical treatment trial.

## DISCUSSION

In this study we demonstrate that American Indian cancer patients receiving PN services while undergoing curative RT as part of their cancer treatment have significantly fewer RT interruptions than their historical counterparts who did not undergo PN. Furthermore, our data reveal a high rate of clinical trial enrollment among AI cancer patients receiving PN services when compared to previous studies which have shown low rates (<1%) of clinical trial participation for AIs.<sup>34, 35, 41</sup> We also describe PN utilization patterns for AI patients receiving cancer treatment to provide insight into the resources necessary to provide cancer treatment navigation services to this or a similar population. Specifically, our study contributes unique information about the number of navigator-patient interactions, the time resources typical of these interactions, and the types of services requested in these interactions during cancer treatment for a population with significant health access barriers. Patients who underwent more intensive treatment regimens tended to more heavily utilize PN services.

Much of the PN literature addressing care of cancer patients focuses on increasing screening incidence and/or decreasing intervals between screening and diagnostic management of initiation of treatment for various cancers,<sup>28-30, 42, 43</sup> and most studies do show improvement in the corresponding outcomes when PN is available. American Indians specifically have been shown to benefit from PN in the setting of facilitating screening and timely diagnostic follow-up.<sup>29, 44</sup> However, few studies report upon the role of PN after a patient is diagnosed and undergoing the rigors of cancer treatment,<sup>30, 45</sup> arguably a time when patients may experience more barriers due logistical complexities and financial burden of receiving many weeks or months of treatment e.g., RT or chemotherapy. Some of the reports that have been published on PN during cancer treatment show improvement in patient satisfaction or decrease in barriers to care.<sup>46, 47</sup> Ell and colleagues<sup>24</sup> showed that treatment adherence was improved compared to previous studies among patients who were randomized to either enhanced usual care (written resource navigation information) or active PN, although there was no statistical difference between the two navigation approaches. Only one other study offers utilization data regarding the types of barriers addressed and the amount of time navigators spend with cancer patients.<sup>48</sup>

Our finding of fewer treatment interruptions for patients undergoing curative RT is one that has important implications for this population that has been shown to have disparately high cancer mortality. It has been demonstrated that prolonged RT interruption is a predictor for loco-regional relapse among patients treated for head and neck cancers.<sup>32, 33</sup> Similarly, it has been established that prolongation of the RT course during treatment for cervical cancer—a disease that disproportionately affects poor and minority women, and for which AI women in the Northern plains have the highest incidence and mortality<sup>6, 49</sup>-- is associated with increased risk for local recurrence and poorer survival outcomes.<sup>31</sup> Patient navigation, in this study, seems to offer an effective strategy to mitigate barriers that may prolong definitive cancer treatment.

Multiple studies have indicated that clinical trial participation among AI cancer patients is low with trial accrual rates of < 1%.<sup>34, 35, 41</sup> Reasons underpinning low minority participation in clinical trials are multi-factorial and may differ across regions as well as between racial/ethnic groups.<sup>50, 51</sup> In this region, it has previously been shown that AI

cancer patients exhibit relatively high rates of medical mistrust and dissatisfaction with prior health care received.<sup>14</sup> Our PN program specifically targets health access barriers in this population and seeks to address them in a culturally-sensitive manner while partnering with tribal communities. This effort toward establishing rapport with AI patients and communities to meet their needs may account for our relatively higher proportion of AI patients willing to enroll on clinical trials.

Our study supports the role of PN in addressing health access barriers to cancer treatment, but it does so with certain limitations. First, our study is not a randomized trial and our analyses did not include a temporally parallel control group against which to compare outcomes. To ensure community-based participation and engagement it simply was not feasible for the purposes of comparison to deny half of AI patients the types of logistical support, financial assistance, and one-on-one advocacy offered by our navigators. In other words, community engagement necessary for the implementation of our effort might have been hindered if we had attempted to provide these services to fewer than all of the patients who desired PN services given the high level of need in the community being served.

More investigation is needed into the impact of PN,<sup>30, 45</sup> and a coordinated, national effort is underway to provide critical insight into the role of PN in cancer care delivery as well as its cost-effectiveness.<sup>52, 53</sup> Until such data are available, data on working models that deliver care effectively via PN provide guidance that can be developed and tailored to various populations.

In conclusion, we have shown that PN is associated with fewer treatment interruptions among AI patients receiving curative RT for their cancer. We have also observed a high rate of clinical trial participation among AI, which have historically been underrepresented in clinical trial research. Furthermore, we characterize utilization specifics for our program to provide insight into resources entailed in administering a PN program in a regional health care center that provides health care to an underserved population. Further research is needed, not only into the cost-effectiveness of PN, but into other metrics of quality of care that may be improved with PN during cancer treatment.

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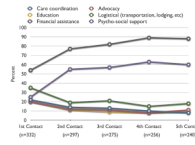
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**Figure 1. Trends in reason for accessing the patient navigator services**  
 The chart shows the percent of patients seeking various types of assistance from patient navigator through the first five contacts with the navigator.

**Table 1**

Sociodemographic characteristics of navigated patients. 332 patients undergoing patient navigation between 2/2004 and 9/2009

<b>Characteristic</b>	<b>number</b>	<b>Percent</b>
Total number of patients navigated	332	
Gender		
Male	151	45 %
Female	181	55%
Median age	60 years	
Range	16-89 years	
Reservation/Tribal community geographical affiliation (not tribal enrollment affiliation)		
Pine Ridge/Oglala Sioux	160	49 %
Rosebud Sioux	61	19 %
Cheyenne River	54	16 %
Standing Rock Sioux	3	1 %
Rapid City (Sioux San)	33	10 %
Other tribal affiliation	18	6 %
Distance lived from cancer center (one way)		
Median	121 miles	
Range	10-444 miles	
Primary payor of medical bills		
Medicare	110	33 %
Indian Health Service	82	25 %
Medicaid	51	16 %
VA	32	10 %
Private insurer	52	16 %
Uninsured	2	1 %
No of patients who do not speak English	5	2%
Speak Lakota language		
Yes	117	36%
No	133	40%
Missing data	79	24%

**Table 2**

Cancer patient and treatment-related characteristics of the 332 navigated patients

<b>Characteristic</b>	<b>number</b>	<b>Percent</b>
Type of cancer		
Breast	74	23%
Lung	50	15%
Prostate	42	13%
Colo-rectal	42	13%
Hematologic	26	8%
Gynecologic	20	6%
Head and neck	21	6%
Gastric/Pancreas/hepatocellular	15	5%
Non-prostate GU (renal, penile, testicular)	18	5%
Sarcoma/Skin	5	2%
Brain	5	2%
Unknown primary site	7	2%
Thyroid	4	1%
Stage at enrollment into PN program*		
In situ disease	7	2%
Stage I	40	12%
Stage II	81	24%
Stage III	66	20%
Stage IV	92	37%
Radiation therapy received/planned	200	60%
At CCI	188	56%
At another facility	12	4%
Treatment intent for those receiving RT at CCI		
Curative	129	69%
Palliative	59	31%
Chemotherapy received/planned	161	49%
Chemo received outside CCI	27	8%
Chemo received at CCI	134	41%
Pt underwent surgery for their cancer		
Yes	167	51%
No	141	43%
Missing	21	6%

**Table 3**

Days of treatment interruption for American Indian patients undergoing curative radiation therapy

	<b>N</b>	<b>Average days of treatment interruption</b>	<b>95% CI (days)</b>
Historical controls (no patient navigation)	70	4.9	2.9-6.9
Patients with patient navigation during treatment	123	1.7	1.1-2.2

CI=confidence intervals