

NIH Public Access

Author Manuscript

J Health Care Poor Underserved. Author manuscript; available in PMC 2013 June 07

Published in final edited form as:

J Health Care Poor Underserved. 2011 November; 22(4): 1331–1343. doi:10.1353/hpu.2011.0115.

A Pre-post Survey Analysis of Satisfaction with Health Care and Medical Mistrust after Patient Navigation for American Indian Cancer Patients

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Abstract

Purpose—To assess the impact of patient navigation (PN) on satisfaction with health care and medical mistrust among American Indians (AI) undergoing cancer treatment.

Methods—This was a pre-post cohort survey study of 52 AI cancer patients who participated in a culturally-tailored PN program during their cancer treatment. Surveys were administered prior to and after cancer treatment assessing medical mistrust and satisfaction with health care using two Likert-type scales.

Results—Participation refusal rate was 7%. Mean scale scores for satisfaction with health care were significantly improved after PN compared with pre-navigation (p<.0001; Wilcoxon signed-rank test). There was no significant difference in the mean scale scores for medical mistrust after PN compared with those observed prior to treatment (p=.13).

Conclusions—American Indian cancer patients who received PN services during their cancer treatment showed improvement in levels of satisfaction with health. However, no improvements were observed in levels of medical mistrust.

Keywords

Patient navigation; medical mistrust; satisfaction with health care; American Indians

As the field of health disparities research evolves from one of documentation of the nature and extent of disparate health outcomes for various racial/ethnic groups to one of exploring solutions, patient navigation has emerged as a potential strategy to overcome access barriers to cancer care in vulnerable populations. The early model for patient navigation during cancer care, established by Freeman and colleagues in Harlem, New York in the early 1990s^{1,2} showed improved overall survival for breast cancer patients in a low-income, innercity population which previously had been shown to have a disparately high cancer mortality rate. Since then, multiple studies have shown improvements in cancer-related health outcomes with use of patient navigators among populations where known health access barriers exist.^{3–10} Most of these studies focus on increasing screening rates or decreasing time intervals to diagnostic resolution of abnormal screening tests. Few studies report on the role or impact of patient navigators during cancer treatment.¹¹

American Indians (AIs) in the Northern plains region of the U.S. exhibit some of the highest cancer mortality rates in the nation.^{12, 13} In 2003, Rapid City Regional Hospital's Cancer

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Care Institute in Rapid City, South Dakota was awarded a National Cancer Institute's Cancer Disparities Research Partnership (CDRP) grant to study and address cancer-related health disparities previously documented in this region where some of the largest reservation-based AI communities are located.^{12–14} Since that time a multifaceted, community-based participatory research and intervention effort, called the Walking Forward Program,^{14–17} has been developed to explore root causes of health disparities, increase cancer screening and education, enroll patients in clinical trials, and provide comprehensive, culturally-tailored patient navigation throughout cancer treatment. An early study from this effort identified the fact that AI cancer patients exhibited relatively higher levels of medical mistrust and lower levels of satisfaction with prior health care among those arriving at CCI for evaluation and treatment.¹⁸ After this finding, we initiated a post-navigation survey study to assess whether patient navigation influenced satisfaction with health care or levels

of medical mistrust among AI patients undergoing treatment at our center. Our hypothesis was that satisfaction with health care would be improved and medical mistrust would be reduced among American Indians who received services of a patient navigator while undergoing cancer treatment.

Methods

Study population

We prospectively surveyed AI patients presenting for cancer treatment and undergoing patient navigation at Rapid City Regional Hospital's Cancer Care Institute in Rapid City, South Dakota between March 2008 and February 2010. This research effort to study the effectiveness of patient navigation in this population was part of a larger NIH grant-funded effort, the Walking Forward Program, described in detail elsewhere.^{15,19,20} The Walking Forward Program is a community-based participatory research and service initiative based at Rapid City Regional Hospital, which is a major secondary and tertiary cancer care provider for not only Rapid City and surrounding areas and the AI population living there, but for the Oglala Sioux Tribe (Pine Ridge), Cheyenne River Sioux Tribe, and Rosebud Sioux Tribe.

For this study, all adult AI cancer patients presenting to the clinic were asked upon registration at the facility by the intake hospital staff if they would consent to being approached by our research staff regarding participation in the surveys. This consent was not informed consent for the patient navigation protocol or for the survey research protocol, but rather a brief intake/patient-contact permission to have non-clinical/research staff contact the patient and have access to their records to determine eligibility for the study. This step was necessary to bridge the clinical side and the potential research side of patients' experiences in this community/regional hospital that did not historically have research as part of its mission. If the patient refused to be approached, then no research staff accessed the demographic or clinical records of the patient as stipulated by the protocol approved by the hospital's institutional review board (IRB). If patients consented to being approached, then eligibility for the survey protocol was later determined by the research staff. Informed consent regarding both patient navigation and the survey study was obtained prior to any demographic or clinical data being collected.

Patients were eligible to be surveyed if they were 18 years of age or older and planning to return to CCI for further care after the initial consultation. Surveys were administered in a face-to-face interview at a subsequent visit during which the patient was already scheduled to return to CCI for a clinical encounter. This was done to minimize inconvenience to the patient in avoiding special visits for survey administration. To minimize survivor bias and bias potentially incurred from contact with the CCI staff, the pre-navigation survey was administered prior to or within two weeks of the initiation of cancer treatment. The goal was to capture attitudes regarding satisfaction with health care experiences and medical mistrust

prior to patient navigation. The post-navigation survey was administered at the end of treatment or at the first follow-up appointment after treatment completion.

All surveys were administered in a face-to-face interview with culturally competent research staff trained in administration of the instrument. Cultural competence was cultivated by ongoing training in place as part of the grant-funded program at Rapid City Regional Hospital Cancer Care Institute.^{14, 15, 19, 20} The instrument as well as the patient navigation and study protocols were approved by the following entities prior to initiation of the study: the IRB of Rapid City Regional Hospital; the IRB of the Aberdeen Area Indian Health Service (IHS); The Oglala Sioux Tribe Research Review 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

All AI cancer patients were offered PN services whereby patients were assisted in navigating the medical system by trained, culturally-competent staff, who have specific training regarding American Indian patients' beliefs and cultural practices—including the unique role of the extended familial network and involvement in care-to serve as advocates through the cancer care continuum starting with presentation for evaluation and treatment. This unique and targeted training was developed specifically to facilitate communication with and trust in medical and ancillary care providers among the AI cancer patients coming to the clinic. The patient navigators assist with coordinating appointments, assisting with insurance difficulties, following up on tests, obtaining medications and specialty services or devices, facilitating transportation and lodging, and offering psycho-social support during treatment. In addition to the hospital-based navigators, the navigation program also includes community research representatives who work closely with the hospital staff and are embedded in the surrounding AI communities. They provide cancer education, network with local heath resources, collect survey data, 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 staff members involved in this effort were either closely connected with or are members of the American Indian communities served by this program. It is our belief that having staff members with such connections or memberships in the tribal communities and working with communities for research and patient navigation program design helps to foster trust between American Indian patients and non-American Indian providers. The AI patients who come to the clinic have access to community members or trained culturally competent staff to serve as liaisons between medical providers should there be identified needs to provide information, education, or facilitate communication between patients and providers. Previously, there were no culturally trained staff members or targeted interventions to provide this enhanced communication between AI patients and their providers. More details regarding the development of this PN program have been provided elsewhere.^{17, 19}

Data source

The data were collected by using a novel instrument developed after review of the literature and meetings with focus groups of AI community members and cancer patients, as well as research program staff of both AI and non-AI background. The domains established for this study were medical mistrust and satisfaction with health care. (The detailed scales and individual items are shown in tabular form in the results section.) The domains to be studied were established by a focus group of eight staff members, which included AIs from the communities, non-AIs, physicians, nurses, and public health practitioners. Once domains were identified, it was determined that use of a previously validated instrument was not

possible because no instrument specific to AIs existed. Furthermore, community participation in this study necessitated that AI community members have a say in the development and approval of the survey instrument. This was accomplished through the initial development focus groups and a subsequent focus group of lay AI community members and cancer patients (not otherwise associated with the Walking Forward Program). The final instrument was vetted in a focus group of American Indian cancer survivors and patients as well as American Indian community members who did not have cancer. This focus group determined that the instrument was culturally responsive and appropriate along with American Indian staff members of our program who were members of the reservation and Rapid City-based American Indian communities served by our program. Whenever possible, items from previously validated and reported surveys were included, modified if necessary, and vetted by the focus groups. The nine-item battery comprising the scale for medical mistrust arose from modification of the Medical Mistrust Index developed by LaVeist and colleagues.^{21, 22} The seven-item scale for assessing satisfaction with health dare was derived from items reported by LaVeist and colleagues^{21, 22} and Zheng and colleagues.²³ Novel items were included in both scales using general principles of survey development.^{24, 25} The process of developing the instrument has been described in detail in a prior peer-reviewed publication.¹⁸

The pre-navigation medical mistrust scale items were exactly the same as the post-treatment scale. Minor modifications were needed to the satisfaction with health care scale for the post-treatment survey to reflect the change in the context of having gone from just receiving a diagnosis of cancer to having just received treatment for cancer. Specifically, three questions were altered. One question (which read, "The first doctor or nurse that told me I had cancer made sure I understood what to do next to get treatment for my cancer" on the pre-navigation survey) was changed to "The doctor or nurse treating my cancer made sure I understood what to do to get treatment for my cancer" on the post-treatment survey. The question that read, "The first doctor or nurse that told me I had cancer listened carefully to my concerns" on the pre-navigation survey was changed to "My cancer doctor listens carefully to my concerns" on the post-treatment survey. The question that read, "Before my first visit to the Cancer Care Institute, there was a doctor or nurse available by phone or in person to answer my questions about my cancer" on the pre-navigation survey was changed to "There is a doctor or nurse available by phone or in person to answer my questions about cancer" on the post-treatment survey. (These corresponding questions and categorized responses are shown in tabular form in the results section.)

Demographic and clinical data were obtained from the medical record as well as from nonscaled descriptive items (such as tribal affiliation, income, employment status, and education level) in the pre-navigation survey. Race and tribal enrollment status were self-reported by the patient.

Study measures

The dependent variables in this study were medical mistrust and satisfaction with health care. Mistrust was measured by the nine-item Likert-type²⁶ scale; respondents were asked to rate their agreement with the items on a five-point scale that included: *strongly agree, agree, I don't have an opinion about this, disagree*, or *strongly disagree*. Scoring range was 1–5 (determined by the means score for items in the scale) with a higher score corresponding to a higher level of mistrust. A seven-item battery using the same five point scale described above was used to measure satisfaction with health care. Categorized results are also presented in tabular form in the results section with scales and items enumerated to provide readers details of the crude data. However, the collapsed categories do not reflect the five-point scales used to calculate the scale scores. The main independent variable was pre*versus* post-navigation status.

Statistical analysis

Data analyses were performed using SPSS version 17.0 (SPSS, Inc., Apache Software Foundation, Chicago, IL, USA). The scales showed good content validity, as determined by the focus group review by both non-AI and AI research staff and non-staff member cancer patients. Internal reliability for each scale was evaluated by Cronbach's alpha.²⁷ The Cronbach's alpha for the mistrust scale was 0.80, and the Cronbach's alpha for the satisfaction with health care scale was 0.87. These values suggest that the scales showed good internal consistency. Mean scale scores for the pre- and post- administration of each scale were evaluated for significance of difference using the non-parametric Wilcoxon signed-rank test for hypothesis testing of repeated measurements on a single sample.²⁸ The categorical data for assessing differences in proportion of patients in-agreement with individual items in the two scales before and after treatment and patient navigation were analyzed using the McNemar's test of marginal homogeneity as this tests the significance of difference in categorical responses in repeated measurements (before vs. after an intervention) on a sample.²⁹ We chose non-parametric test as these tests make fewer assumptions about the distribution of responses among patients using these scales, as we cannot rely on the data belonging to a particular or normal distribution.

Results

Survey participation and characteristics of the study population

Of the 233 AI cancer patients invited to participate in the survey 17 (7%) declined. Another 118 were deemed ineligible to participate due to having previously received cancer treatment outside CCI or for a prior cancer episode (59 patients); were not receiving any further treatment after initial consult at CCI (27 patients); or had already undergone two weeks of chemotherapy, radiation therapy, or both for two weeks for their current cancer episode before the survey could be administered (32 patients). Of the remaining 98 patients who completed the pre-treatment survey at the time of this analysis, 52 patients had also finished treatment, returned for follow-up, and completed the post-navigation survey. These 52 patients constitute the study cohort for this analysis. All patients who completed both surveys had also received patient navigation during their cancer treatment. Sociodemographic characteristics of the study population are shown in Table 1. Compared with the baseline American Indian population data for this region, our cohort had a higher median income (\$16,900 vs. \$6,000-7,000 per annum) and a higher employment rate compared with a population whose unemployment rate can range from 80–85%. However, the proportion of patients in our study living below the federal poverty level (46%) was comparable to the baseline rate of 49% for American Indians in this region.³⁰

Medical mistrust and satisfaction with health care before and after navigation

The mean scale score for satisfaction with health care was significantly higher after patient navigation compared with scores prior to navigation (p<.0001) with an increase of 0.41 (95% CI, 0.22–0.60) in the mean scale score. There was no significant difference (p=.13} in the mean scale score for medical mistrust, as shown in Table 2. The individual items for the satisfaction with health care and the medical mistrust scales as well as the categorized proportion of patients expressing agreement with each item before and after patient navigation are shown in Table 3 and Table 4, respectively. For the scale regarding satisfaction with health care, there were significantly higher proportions of patient agreeing with the following statements on the post-treatment survey compared with the pre-treatment responses: "The hospital or clinic I usually go to provides me with good health care over all" (96% *vs.* 83% agreement, p=.04); "The medical care providers I usually see treat me with dignity and respect" (100% *vs.* 85% agreement, p=.005); "Ihe doctor or nurse treating my cancer made sure that I understood what to do to get treatment for my cancer" (98% *vs.* 85%

agreement, p=.008); "My cancer doctor listens carefully to my concerns" (100% *vs.* 89% agreement, p=.01); and "There is a doctor or nurse available by phone or in person to answer my questions about cancer" (96% *vs.* 75% agreement, p=.002). As seen in Table 4, there were no significant differences in the categorical responses indicating agreement with any of the items in the mistrust scale.

Discussion

We found that American Indian cancer patients at our center expressed higher levels of satisfaction with health care after undergoing cancer treatment while receiving services of a culturally competent patient navigator. Conversely, we saw no change in the mean score for the medical mistrust scale after patient navigation when compared with scores from surveys administered prior to patient navigation.

Other investigators have shown that American Indians exhibit relatively high levels of medical mistrust and low levels of satisfaction with health care, ^{31–33} however no studies have specifically studied how interventions, such as patient navigation, may affect these attitudes in this population during treatment for disease. As implementation of patient navigation programs has become more widespread, some authors have reported improvement in satisfaction with health care among other populations. Ferrante and colleagues⁸ reported improvement in satisfaction with health care among a cohort of urban, minority (predominantly African American and Hispanic) patients who underwent patient navigation through diagnostic resolution of abnormal mammogram results. Investigators in Canada also showed a significant improvement in satisfaction with care, specifically as related to doctor-related and waiting time concerns, among patients who received the services of a patient navigator during treatment for head and neck cancer. American Indians in the Northern Plains have documented relatively high cancer mortality rates^{12, 13} and to the extent that improving patient-reported outcomes in quality of care influences other metrics such as better rates of treatment completion, reduced treatment interruptions, or improved communication with providers to identify and address barriers, patient navigation may play a role in mitigating cancer disparities among AI cancer patients in this region.

Our finding that the level of medical mistrust was not significantly different after receiving care with a patient navigator from what it was prior to receiving navigation raises two important considerations. The first concern is that our cultural-competence and training process should be honed to address the underlying levels of medical mistrust that exist in this population.^{18, 31–33} The second consideration arises from the potential influence history exerts on attitudes toward a largely non-Native American-administered health care system. Specifically, the 500-year history of colonization, its implications for health in American Indian communities, and the persistence of health disparities in this population which have sometimes been exploited for resource-advantage,³⁴ may play as much a role in determining trust in medical provision as do the interactions with individual medical care providers. In other words, it may be unrealistic to expect the presence of patient navigators to overcome this trust barrier appreciably over the time-frame of a course of cancer treatment.

We acknowledge limitations of our small cohort study. Most notably, our ability to draw conclusions about the role that patient navigation itself played in the observed improved levels of satisfaction is limited by the fact that we did not have a comparison cohort of patients who did not receive patient navigation against which to compare survey results. Given the extensive services offered by our patient navigation program (which include financial, transportation, and lodging support) it is not feasible in this socio-economically challenged population to have a control group of patients who are not offered these services during cancer treatment for the purposes of research. As with all survey studies, response

bias may have been present in the post-navigation survey in as much as respondents may have been inclined to provide positive answers to the satisfaction scale items in order not to offend or extend negative feedback to the navigators (who often administered the survey). However, the fact that there were no significant improvements to the scale scores for medical mistrust argues against the possibility that respondents tended toward socially desirable response bias. Finally, while we did show a statistically significant improvement in satisfaction with health care in our study, we acknowledge that the statistical improvement may not always translate to meaningful clinical improvement.

In conclusion, we observed improved satisfaction with health care among American Indian patients receiving patient navigation during cancer treatment. This finding suggests that patient navigation may be an effective health care delivery intervention for improving patient-reported outcomes in this population with known cancer-related health disparities. Findings regarding the lack of impact upon medical mistrust after patient navigation among patients in our study suggest the need for programmatic review of our patient navigation effort, specifically with regard to training and cultural competence preparation of patient navigators to address the special historical and cultural concerns of this vulnerable population. Further studies are needed with larger numbers of patients to assess how patient navigation may improve quality of care for this and other vulnerable populations.

Notes

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SOCIODEMOGRAPHIC CHARACTERISTICS OF THE STUDY POPULATION

Characteristic	Number (%)
Sex	
Male	31 (60)
Female	21 (40)
Median age (years)	62
Range	24–79
Education	
Less than high school	12 (23)
High school/GED or more	40 (77)
Median annual income (\$)	16,900
Range	0-100,000
Annual income (\$) ^a	
<10,000	16 (32)
10,000–24,999	12 (24)
25,000-50,000	16 (32)
>50,000	6(12)
Below federal poverty level ^{a}	
Yes	23 (46)
No	27 (54)
Primary payor of medical bills	
Medicare	16 (31)
Veterans Administration	11 (22)
Indian Health Service	10 (20)
Medicaid	8(16)
Private insurer	6(12)
Employment status	
Yes	13 (25)
No	15 (29)
Retired	24 (46)

^a2 pts did not supply income data.

MEAN SCALE SCORES FOR SATISFACTION WITH HEALTH CARE AND MEDICAL MISTRUST BATTERIES PRE- AND POST-PATIENT NAVIGATION

Scale	Pre-navigation (std dev)	Post-navigation (std dev)	p value ^a
Satisfaction w/health care b	4.12 (0.65)	4.53 (0.43)	<.0001
Change in mean score (95% CI)	+0.41 (0.22-0.60)		
Medical mistrust ^C	2.38 (0.42)	2.23 (0.59)	.13
Change in mean score (95% CI)	-0.13 (-0.28-0.03)		

^aWilcoxon signed ranks test (non-parametric).

 b A higher score corresponds to a higher level of satisfaction with health care and health care providers.

 c A higher score corresponds to a higher level of mistrust of the health care system and health care providers.

CI = Confidence Interval

SATISFACTION SCALE: INDIVIDUAL ITEMS AND RESPONSES

	Pre-treatment No. (%)	Post-treatment No. (%)	p value
The hospital or clinic I usually go to provides me with good health care over all.			
Agree ^a	43 (83)	50 (96)	.04
Neutral/disagree ^b	9 (17)	2(4)	
The medical care providers I usually see treat me with dignity and respect.			
Agree	44 (85)	52 (100)	.005
Neutral/Disagree	8(15)	0	
I feel comfortable talking to doctors when I have a health problem.			
Agree	46 (89)	47 (90)	.71
Neutral/Disagree	6 (12)	5 (10)	
PRE: The first doctor or nurse that told me I had cancer made sure I understood what to do next to get treatment for my cancer.			
POST: The doctor or nurse treating my cancer made sure I understood what to do to get treatment for my cancer.			
Agree	44 (85)	51 (98)	.008
Neutral/Disagree	8 (15)	1 (2)	
PRE: The first doctor or nurse that told me I had cancer listened carefully to my concerns.			
POST: My cancer doctor listens carefully to my concerns.			
Agree	46 (89)	52 (100)	.01
Neutral/Disagree	6(12)	0	
PRE: Before my first visit to the Cancer Care Institute, there was a doctor or nurse available by phone or in person to answer my questions about cancer.			
POST: There is a doctor or nurse available by phone or in person to answer my questions about cancer.			
Agree	39 (75)	50 (96)	.002
Neutral/Disagree	13 (25)	2 (4)	
If I have a question, my doctor will give me a straight answer.			
Agree	49 (94)	51 (98)	.32
Neutral/Disagree	3 (6)	1 (2)	

 a Agree = Strongly agree + agree.

 $b_{Neutral/Disagree = neutral + strongly disagree + disagree.}$

MISTRUST SCALE: INDIVIDUAL ITEMS AND RESPONSES

	Pre-treatment No. (%)	Post-treatment No. (%)	p value
Hospitals and clinics often want to know more about your personal business than they really need to know.			
Agree ^a	17 (33)	17 (33)	1.00
Neutral/disagree ^b	35 (67)	33 (64)	
Missing	_	2 (4)	
In the past, clinics and hospitals have done harmful things to patients without their knowledge.			
Agree	12 (23)	17 (33)	.26
Neutral/Disagree	40 (77)	34 (65)	
Missing	_	1 (2)	
At hospitals and clinics rich patients receive better care than poor patients do.			
Agree	15 (29)	8 (15)	.14
Neutral/disagree	36 (69)	44 (85)	
Missing	1 (2)	_	
I worry that doctors and nurses will do experimental studies on me without telling or asking me.			
Agree	7 (14)	4 (8)	.38
Neutral/disagree	44 (85)	48 (92)	
Missing	1 (2)	_	
I have put off getting medical care when I have had health problems because I do not trust doctors and nurses.			
Agree	4 (8)	3 (6)	1.00
Neutral/disagree	47 (90)	49 (94)	
Missing	1 (2)	_	
I have put off getting medical care in the past because I felt that I would be treated disrespectfully.			
Agree	4 (8)	5 (10)	1.00
Neutral/disagree	47 (90)	46 (89)	
Missing	1 (2)	1 (2)	
I usually trust doctors.			
Agree	44 (85)	50 (96)	.18
Neutral/disagree	7 (14)	2 (4)	
Missing	1 (2)	_	
Hospitals are places where people go to die.			
Agree	4 (8)	4 (8)	1.00
Neutral/disagree	47 (90)	48 (92)	
Missing	1 (2)	_	
People should always follow the advice given to them at hospitals.			
Agree	42 (81)	43 (83)	1.00
Neutral/disagree	9 (17)	9 (17)	
Missing	1 (2)	_	

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 $b_{\text{Neutral/Disagree} = \text{neutral} + \text{strongly disagree} + \text{disagree}.$