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Identifying Health Literacy and Health System Navigation Needs Among Rural Cancer Patients: Findings from the Rural Oncology Literacy Enhancement Study (ROLES)

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Abstract

Rural residence is associated with disparities in cancer-related outcomes. Guided by the Chronic Care Model (CCM), the Rural Oncology Literacy Enhancement Study (ROLES) assessed health literacy and patient navigation needs among rural cancer patients. A mixed methods (qualitative and quantitative) approach was used, including: in-depth interviews, health literacy assessments, and phone surveys with cancer patients (N=53) from 5 oncology clinics in rural Wisconsin; focus groups and self-administered surveys with staff (N=41) in these clinics. Within four dimensions of the CCM (community resources, self-management support, delivery system design, and decision support), this study uncovered multiple unmet navigation needs, health literacy limitations, and barriers to quality cancer care. System-level implementation of patient navigation and health literacy best practices could contribute to improved cancer care and patient outcomes among rural populations. Further research identifying effective interventions that reduce cancer disparities among rural cancer patients is necessary.

INTRODUCTION

Health literacy is an emerging area of research in the delivery of quality cancer care, with important implications for patient provider communication and care coordination. Health literacy refers to individuals' ability to understand and act upon basic health information and services, the health literacy environment of healthcare facilities, and healthcare linkages to community resources [1–2]. Health literacy is a predictor of poor overall health and mortality among older adults [3–4]. Although limited health literacy is more prevalent among the elderly, minorities, low-educated, low-income, and rural populations, health literacy skills can decline under stressful circumstances and illness [5–6].

Health literacy has been recognized as a critical factor affecting the continuum of cancer care, from prevention and screening, to explanations of diagnoses and treatments [7]. It may also affect cancer patients' adherence to treatment, understanding of treatment goals

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(curative vs. palliative), and health-related decision making [7]. Cancer patients with low or moderate health literacy are at risk of poor decision outcomes and more likely to report low levels of perceived care coordination and low satisfaction with care coordination [7–8].

Rural cancer patients represent 21% of cancer survivors in the United States and tend to be older, less educated, and of lower socioeconomic status compared to their more urban counterparts [9–10]. Due in part to these sociodemographic characteristics, cancer patients in rural areas are more likely to experience health literacy barriers and less likely to make shared decisions with their treatment staff than patients in more urbanized areas [10–11]. These differences, along with other factors, such as poorer medical care infrastructures, lower physician availability, transportation barriers, and limited availability of formal support systems, may contribute to observed disparities in cancer morbidity and mortality among rural populations [9–12].

Little is known about the health literacy barriers and system navigation needs experienced by cancer patients in rural areas of the U.S. This study identified the health literacy barriers and patient navigation needs of rural cancer patients in Wisconsin using the *Chronic Care Model* as a guiding and integrative framework. This information was gathered to inform the design and implementation of future programs that could improve rural patients' outcomes and quality of care.

The Chronic Care Model

The *Chronic Care Model (CCM)* is a framework aimed at improving health care delivery for chronic conditions and, more recently, cancer care [13]. The CCM recognizes patient outcomes are influenced by six interconnected components: 1) the health care system; 2) the community in which the health care system is embedded and available resources; 3) self-management support; 4) delivery system design; 5) decision support; and 6) clinical information systems [14]. Health literacy is a systems and individual-level concept [1]. It is integral to each dimension of the CCM, whose goal is to aid in the provision of health care services that result in productive interactions between motivated patients and caregivers and well-prepared and proactive health care teams.

METHODS

Design and participants

A mixed methods approach was used to identify needs, barriers, and resources among cancer patients treated in five independent rural hospitals or clinics that receive outreach oncology services from a university-based comprehensive cancer center located in the Midwest. Data on patients' health literacy levels and barriers, patient navigation needs, and quality of cancer care were obtained through in-depth interviews, phone surveys, and health literacy assessments. Focus groups and surveys with clinical staff were also conducted. Data collection occurred between December 2010–June 2011.

A purposive sampling strategy was used to recruit a sample representative of both genders, different age groups, and cancer types. Eligibility criteria were: (1) 18 years of age or older; (2) diagnosed with primarily breast, lung, colorectal, or prostate cancers; (3) currently receiving cancer care at the study clinic; and (4) ability to give informed consent. All clinical staff working at the oncology units of the study clinics, including the visiting oncologists from the comprehensive cancer center, were eligible and invited to participate in study focus groups and organizational health literacy self-assessments.

Procedures

Patients and their caregivers were recruited on the day of their oncology or chemotherapy appointment by nurses. Patients who agreed to participate in the study met privately with a member of the research team. The purpose of the study was explained and informed consent was obtained. Face-to-face, semi-structured interviews were conducted covering the topics detailed in Table 1. Following the interviews, the researcher administered the Short Test of Functional Health Literacy in Adults (STOFHLA) [15]. Administration of the interview and the STOFHLA ranged from 45 minutes to 1 hour. Within a few weeks of the interview, patients completed a survey over the phone with a member of the research team. The 30 minute survey consisted of closed-ended questions, based partly on the Consumer Assessment of Healthcare Providers and Systems and the Assessment of Cancer Care and Satisfaction surveys [11,16]. The survey covered (1) patients' history and satisfaction with cancer care, (2) provider communication, (3) health literacy barriers, (4) patient support, (5) decision making experiences, (6) trust in providers, and (7) patient demographics and clinical information. Overall, 53 patients were interviewed and among them, 30 completed the STOFHLA assessment and 51 completed the follow-up phone survey.

A focus group with clinic staff was conducted in each of the five clinics. Participants included oncologists, nurses, licensed practical nurses, pharmacy staff, unit clerks, front desk staff and social workers. Staff were recruited through fliers, announcements, word of mouth, and email communication. A semi-structured guide was used to assess communication, psychological, logistical, financial, and access to care and/or medicine barriers cancer patients' may encounter. Focus group participants completed a questionnaire including demographics and questions rating individual and clinics' use of health literacy best practices [2]. Forty-one clinic staff members participated in the focus groups and completed the health literacy survey. All procedures were reviewed and approved by the authors' Institutional Review Board.

Analysis and Interpretation

All interviews and focus groups were audio recorded transcribed by research team members or a hired professional. Participants' names and other identifying information were masked in the transcriptions. All transcripts (focus groups and interviews) were reviewed and coded, using a mixed deductive and inductive approach, by a trained researcher. Two additional research assistants reviewed the coding and emerging themes. These three research members met frequently to compare codes and emerging themes. Discrepancies were resolved by reconciliations and discarding. Frequency and salience of different themes identified as relevant from a health literacy perspective were analyzed and integrated using the CCM framework.

Quantitative data from the phone surveys, STOFHLA, and staff health literacy self-assessments were analyzed using IBM SPSS Statistics version 20.0.0 (IBM Corporation, Armonk, NY). Descriptive statistics (mean, standard deviations, and percentages) were computed. The results were integrated with the qualitative analyses.

RESULTS

Characteristics of the study participants are shown in Table 2. The majority of patients were female (63%), non-Hispanic White (96%), and married (71%). Clinic staff were also mostly female (90%). Our study identified health literacy and patient navigation needs within each dimension of the CCM. In this paper, we report and discuss the results aligned with four of these dimensions: the community in which the health care systems are embedded; self-management support; delivery system design; and decision support [14]. These components

have direct implications for future efforts to address health literacy barriers and navigation needs experienced by rural cancer patients.

Community Characteristics

Stoicism and self-reliance—Throughout the patient and staff narratives, cultural values of stoicism, pragmatism, independence, privacy, and self-reliance emerged. These values were often in conflict with patients' needs resulting in patients “suffering in silence” rather than seeking help. For example, many patients refrained from contacting the clinics when they experience pain or treatment side effects because they do not want to “*bother*” busy nurses and doctors. Our survey data reflected that only 28% of patients had called the clinic with a medical question in the previous 12 months (Table 3). One staff member reported:

“[...], if I don't ask, they're not gonna tell me. So I try to approach the topic right away so that [...] I'm not going to find out three treatments down the road that they really couldn't buy their own food.”

Limited resources—Rural communities have limited availability of formal support services for cancer patients. Since diagnosis, only 12% of patients had participated in a support group and only about 26% expressed interest in participating in one. Patients preferred to rely on family, friends, neighbors, co-workers, and/or religious institutions for support. Approximately 37% of patients reported receiving support from religious organizations. Staff recognized the need for improved linkages with community resources. Only 55% of staff reported that they are “doing well” with maintaining an updated list of community resources and referring patients as needed, while 70% reported they “need improvement, are not doing, or are not sure” with helping patients to access community-based programs (Table 3).

Self-management support

Some findings reflected opportunities for improvement with self-management support practices, that is, the process of engaging patients (and their families) to more fully participate in cancer care.

Patient health literacy—Of the 53 patients who were interviewed, 56% completed the STOFHLA and, among them, all reported adequate health literacy levels. Of the 44% who did not complete the STOFHLA, 34% complete only parts of the test and 10% refused to complete the test (Table 3). Reasons for refusal or partial completion included fatigue, not feeling well, being on medication, and forgetting their glasses.

Understanding medication and medical information—Across all sites, staff reported that patients struggle with understanding the purpose of tests, procedures, medications, and treatment plans and outcomes. Fifty-seven percent of the patient sample reported that cancer treatment staff sometimes used medical words they did not understand. Staff reported patients' emotional trauma impedes their care and many fear overmedication. They indicated that patients are too overwhelmed and scared to process information and/or ask questions during their appointments. They perceived that many patients would “*rather say nothing*” than “*admit*” that they do not understand something their doctors or nurses have told them about their diagnoses, treatment, or medications. For example, one patient reported:

“Like my pain medicine. They (clinic staff) just say take one per day for pain, you know. There are a lot of my pills they just say take one per day, for what? I have like 20 bottles of pills and only three of them (pill bottles) tell what it is for and then the rest I have to sit there and you know try to remember,”

Delivery System Design

Care coordination—Staff members discussed the need for greater levels of care coordination in order to meet the multiple needs of cancer patients as they transition across providers, departments, and even systems. According to clinic staff, fragmentation of care has resulted in duplication of tests ordered and medications prescribed. Staff and patients reported that the burden of recounting medical histories, diagnoses, treatment plans, test results, procedures, is frequently placed on patients, who may or may not accurately relay the information to their providers. One staff member explained:

“Doctors within the clinic are not connected with each other. [Family docs and oncologists] aren't even in the same system and don't share info or med lists in-house. Patients end up getting duplicates, even triplicates...of narcotics prescriptions.”

Assessing and mitigating non-medical needs—Cancer patients often deal with concomitant social, emotional, and financial needs that can impact treatment adherence, health outcomes, and quality of life. In some cases, social and financial concerns of patients occurred after the initiation of treatment leading to disruption of the treatment plan. As reported by one patient:

“There's another girl I know of who's going through more chemo now. I met her through the support group and that was a big thing with, you know—jobs—you know, being laid off and insurance being dropped and how would she be able to keep seeing [her doctor] with no insurance in, you know?”

None of the clinics had a system to routinely screen patients for social, emotional, or financial needs. Consequently, nurses are burdened with addressing non-medical needs on an ad hoc basis. Only 45% of staff reported that they are “doing well” at assessing patients non-medical needs and providing support or referrals. Frequently, patient care would be interrupted or impacted by non-medical needs leaving gaps in care that nurses try to accommodate. Nurses were frequently taken from their primary responsibilities of patient care and education. Staff did not always utilize social workers or counselors early in patients' treatment plan, if at all. Patients' reports and answers to the phone survey corroborated the limited use of other professionals to address these additional needs (Table 3). One staff member stated:

“We could really use a person that would have a little time to talk to the patient and find out what their concerns are.”

Clinic forms—Interviews revealed that many patients thought that consent forms should be shorter, simpler, contain less medical jargon, and be administered less frequently. Patients reported clinic staff frequently explained the forms. Fifty-one percent of patients replied that staff always offered help in filling out forms. Notably, 54% reported ever having signed a clinic form without reading it. Some patients placed a significant amount of trust in their physicians and believed the prescribed treatment was best. Others felt they had no choice in treatment, must sign consent forms, otherwise they would not receive treatment. As one patient reported:

“I have signed a lot of papers without reading. I figure they ain't gonna give me nothing to sign if it's bad.”

Decision Support

Decision support relies on the notion that quality clinical care must be consistent with scientific evidence and patient preferences. Evidence-based guidelines and information must

be shared with patients using proven provider education methods to encourage their participation [17]. Some findings from our study suggested the need to improve patient involvement in the decision-making process and promote continued provider education methods.

Shared decision-making—In our sample, patients described having cancer care as a “foreign” experience and subsequently had difficulty anticipating the kinds of questions to ask about their clinical options. In the interviews, patients reported wanting more partnership in medical decision-making and more information about their treatment options (i.e. their costs and benefits), treatment plans, timelines, and outcomes. Survey data indicated that, although 76% of patients reported decisions regarding their treatment were made by both the patient and the cancer treatment staff, 14% reported that the treatment staff made these decisions and 10% reported that the patient him or herself made treatment decisions. Patients reported a preference for “approachable” doctors who validated their concerns or questions and made them partners in care planning. One patient reported that her doctor makes her feel like “part of the team”, that she “knows what he’s talking about”, and that respect “makes a big difference” to her.

Patient empowerment—Staff responses to the survey reflected that only 40% were “doing well” at working with patients to set priorities and develop action plans to promote behavior change. Seventy-six percent of clinic staff reported that they were “doing well” at creating an environment that encouraged patients to ask questions and 65% reported they were “doing well” with asking patients if they needed extra support and offered to work together with patients. In contrast, only 49% reported they were “doing well” with suggesting that patients write down questions while waiting for appointments.

Verbal communication strategies—Best practices for improving the effective provision of medical information include avoiding medical jargon, using graphs or visual aids, and frequently assessing understanding and attention [18]. Forty-one percent of patients reported that cancer treatment staff never used pictures, drawings, or models to explain things to them. Staff acknowledged limited use of best patient-provider communication practices such as “teach-back” (30%), using visual aids (12%), and avoiding medical jargon when communicating with patients (49%). Additionally, 90% of staff reported a need to improve awareness and sensitivity training about health literacy issues. One patient described how she felt during her first visit with the oncologist:

“[The doctor] was rattling off all these things that I needed to do...and my brain just shuts off. It was overload.”

DISCUSSION

This study assessed the health literacy and patient navigation needs of cancer patients in 5 oncology clinics serving rural Wisconsin. Health literacy and patient navigation needs were identified across multiple components of the CCM. These included limited or irregular referrals to support services within the clinic (e.g., social work, mental health, nutritionist), disjointed care coordination within and across facilities, problems understanding and managing medications, the absence of systematic assessments of non-medical needs, and little utilization of best practices for patient-provider communication. Cultural norms of stoicism and independence suffuse each level of the CCM. These norms influence help-seeking behaviors and patients' comfort with, and willingness to ask, questions of their healthcare providers. Unmet patient needs and barriers to optimal cancer treatment may stem from the limited availability of and links to formal support services as well as patients' reliance on informal support networks (family, friends, faith communities).

These findings are consistent with previous research documenting health disparities among rural cancer patients, such as, decreased access to specialty doctors, limited availability of formal support systems, and gaps in the medical care infrastructures [12,19]. Our study identified limited use of best patient-provider communication practices as important barriers to quality cancer care. This highlights the need for interventions to improve patients' understanding of their diagnoses, treatment plans, and management of side effects, particularly pain. Cancer patient navigation needs identified in this study mirror those found in other studies, especially needs relating to self-management, decision support, psychosocial, and finances that often arise during cancer treatment [13].

Health literacy needs (e.g., help with forms, understanding written health materials), limited access to formal support services, and cultural norms of stoicism may exacerbate the navigation and self-management needs identified in this study. Similar to other studies examining mental health in rural areas, participants in this study were reluctant to admit they were struggling and/or engage in help-seeking behavior [20]. These issues highlight the need for novel systems-level and interpersonal-level approaches of rendering care that are tailored to the cultural norms of rural cancer patients.

The IOM has issued two reports advocating the need for more health literate care systems and patient-centered care [1,19]. The need for increased cancer coordination and mitigation of non-medical needs in cancer care has also been widely recognized by cancer researchers, practitioners, and patients and has fuelled the development and implementation of patient navigation interventions [8,13,21–23]. Patient navigation represents a promising strategy to reduce barriers to optimal care, quality of life, and disparities in cancer care among rural cancer patients [21–22]. Patient navigation programs focus on ensuring patient understanding of the health care system, diagnoses, treatment plans, and adherence to care. These programs provide cancer patients with education and address concerns (psychological, social, physical) that may serve as barriers to optimal cancer care and better quality of life [22–23]. Navigators, typically nurses, serve as a point-of-contact between patients and the health care system. They help coordinate care, facilitate communication across providers and settings, and connect patients with resources within and outside the clinical setting [24].

Research indicates that patient navigation programs have a positive effect on adherence to cancer screening, timeliness of care, utilization of cancer counseling services, and quality of life [23,25]. Studies have shown an association between navigation programs and decreased barriers to care, including fewer treatment interruptions [21–23]. Patient navigation has also been found to increase satisfaction with care among cancer patients experiencing financial, education, and/or language barriers [23,26]. However, despite a growing number of studies focused on the impact of patient navigation programs on cancer care and patient outcomes, evidence on the effectiveness of these programs in rural cancer care settings is limited. Few studies have tested care coordination and barriers-focused navigation programs with rural cancer patients [21,27]. Given cancer health disparities present in rural areas and the unmet needs identified by our study, more research on the effectiveness of patient navigation programs in rural cancer settings is imperative [9].

Results from our study underscored the need for interventions to improve patient-provider communication among rural cancer patients. Effective patient-provider communication has been integral to patient-centered cancer care and is correlated with improved patient outcomes [28–29]. Provider training in and adoption of health literacy and communication best practices could improve patient-provider communication, rural patients' empowerment, and cancer care self-management. Provider-directed training using effective communication strategies of patients with low literacy has shown positive effects on colorectal cancer

screening [30]. However, further research is needed to document the impact of these interventions on a broader population of cancer patients, including those treated in rural oncology clinics.

This study is subject to several limitations. The clinics included in the study are affiliated with a major cancer center located in the Midwest and the results could be different for cancer patients in rural areas receiving care in other facilities. Definitions of rural versus urban vary depending on the source and purpose. The cities where the study clinics were located ranged in population from 4,433 to 16,243 thereby meeting the US Census definition of rural. Patients and staff who participated may not fully represent the patient and staff populations in all rural cancer care settings. All data are based on self-report and may be affected by information, recall, and social desirability biases. Patient interviews, STOFHLA assessments, and staff focus groups took place in the facilities where patients' received care. Many of the participants were undergoing chemotherapy while the interview and STOFHLA were conducted. Patients' fatigue, stress, and physical well-being as well as the oncologists' schedules on any particular day resulted in no or partial completion of the STOFHLA by some patients. Reasons for not completing the instrument included fatigue, stress, and/or feeling side effects from chemotherapy. For 11% of patients, the reasons for incompleteness are unknown. When missing data for incomplete or partially completed tests are coded as 0 (N=53), 19% patients have inadequate, 6% have marginal, and 75% have adequate health literacy. Collection of data in a clinical setting may also have increased bias of the patients and staff reports. We attempted to address this potential bias by conducting patient surveys over the phone and using anonymous self-administered staff surveys. The consistency between the themes emerging from patient interviews and staff focus groups, as well as the correlation with quantitative data from patient and staff surveys, increase the validity of the results. Future research in other rural cancer care settings should be conducted to corroborate these findings.

In summary, our study uncovered multiple unmet navigation needs and health literacy barriers to quality cancer care among rural cancer patients. Health literacy and its attendant effects on patients, providers, and delivery of care is a cross-cutting systems issue [19]. Implementation of patient navigation programs and adoption of health literacy best practices among systems and providers could contribute to improved cancer care delivery and cancer-related outcomes among rural populations. Further research of system-level interventions on cancer patient outcomes, disease management, and satisfaction is imperative to address the gaps highlighted in our study and to reduce rural cancer disparities.

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Table 1**In-depth, semi-structured patient interview topics and sample questions**

In-depth patient interviews	Sample questions
General opinions about the oncology clinic	<ul style="list-style-type: none"> • <i>What is your general opinion of the care you have received so far in this clinic? What do you like about it? What do you dislike?</i> • <i>Looking back, since you were diagnosed with cancer, what do you wish had been different? Probe: What do you wish you had had more help with?</i>
Communication with health care providers	<ul style="list-style-type: none"> • <i>How do you feel about the communication between you and the doctors in this clinic? How could communication with them be improved?</i> • <i>How do you feel about the way the doctor or nurses described the treatment to you? What would you suggest to improve their explanations?</i>
Opinion on patient education materials	<ul style="list-style-type: none"> • <i>Have you received any written materials about the type of cancer you have from the clinic? What do you think about this/these material/s?</i>
Care coordination	<ul style="list-style-type: none"> • <i>Do you have a treatment plan written out for you to refer to?</i> • <i>Who else is involved in your cancer care?</i> • <i>Do you use support services in the community? Why or why not?</i>
Self-management support	<ul style="list-style-type: none"> • <i>Have you ever sat with your doctor or nurse and gone over all of your medications, their purpose, and how and when you need to take them?</i>
Health literacy barriers experienced	<ul style="list-style-type: none"> • <i>Since you were diagnosed with cancer, have you ever made mistakes with your medication?</i> • <i>Have you been asked to fill out health history forms in [Name of Clinic]? In general, what do you think of those forms? Why?</i> • <i>Have you ever filled out consent forms? Do you have suggestions for making these forms easier to fill?</i>
Other barriers to cancer care	<ul style="list-style-type: none"> • <i>Is there something else we haven't talked about that has made it difficult for you to get cancer care? What has helped you cope with these difficulties?</i>

Table 2

Characteristics of the study participants

Patients	%	N *
Gender (female),	63	51
Age, Mean (Range)	62 (39 – 86)	51
Race/ethnicity (non-Hispanic white)	96	51
Marital status (married/cohabiting)	71	51
Education		51
• Did not complete high school	16	
• High school	49	
• Some college or higher	35	
Household income (less than \$30,000 per year)		50
• Less than \$15,000	22	
• \$15,000 – \$30,000	24	
• \$30,000 – \$50,000	32	
• More than \$50,000	22	
Employment status prior to cancer (full time employed)	45	51
Employment status at time of the survey (full time employed)	20	51
Living with children,	14	51
Type of cancer		51
• Breast	45	
• Lung	22	
• Colorectal	24	
• Prostate	6	
• Other	4	
How long treated at oncology clinic		51
• Less than 6 months	35	
• Between 6 months and 1 year	22	
• Between 1 and 3 years	16	
• 3 or more years	26	
Treated for cancer exclusively at study clinic	94	51
Number of visits to oncology clinic during past 12 months		50
• 1–4	34	
• 5–9	16	
• 10 or more	50	
STOFHLA score		53
• Adequate	56	
• Inadequate, Marginal, or Unknown	44	
Clinic staff	%	N
Gender (female)	90	41
Age, Mean (Standard Deviation)	49 (9.5)	40

Current position		41
• Oncology doctor	7	
• Oncology nurse	32	
• Nurse	5	
• Medical assistant	2	
• Other	10	
• Unknown	44	
Time on current position (years), Mean (Standard Deviation)	10 (8)	35

* Sample sizes vary due to missing responses to the patient and staff surveys.

Table 3

Summary of responses to patient and staff surveys

Community resources and culture	%	N *
(P) Called the clinic with a medical question during past 12 months	28	51
(P) Participated in a cancer support group	12	51
(P) Would be interested in participating in a support group for cancer patients	26	46
(P) Received support from religious organization	37	51
(S) Clinic needs to improve **: <ul style="list-style-type: none"> • Maintaining an updated list of community resources and referring patients as needed • Helping patients to access community-based programs 	45 70	40 39
Self-management support	%	
(P) Inadequate, marginal, or unknown level of health literacy, assessed by STOFHLA	44	53
(P) Have made a mistake taking their cancer medication	16	45
(P) Always/sometimes have trouble filling out medical forms by themselves	37	43
(P) Always/sometimes have trouble understanding written materials given by cancer treatment staff	47	43
(P) Treatment staff never/sometimes asks patient to repeat how they are going to take their medication	71	45
(P) Treatment staff always/sometimes uses medical words they do not understand	57	51
(P) Treatment staff always/sometimes talks too fast	16	51
(S) Clinic needs to improve **: <ul style="list-style-type: none"> • Reviews medication with patients at each appointment • Pilot testing new written materials for appeal and comprehension • Using patient education materials designed to be easy to read • Discussing different methods for patients to take medications correctly 	30 95 60 60	40 41 40 40
Delivery system design	%	
(P) Treatment staff never/sometimes follow up with patient to give test results	14	51
(P) Results of tests are never/sometimes easy to understand	30	51
(P) Follow-up instructions are never/sometimes easy to understand	18	51
(P) Staff never/sometimes offers help filling out forms	37	43
(P) Have signed a clinic form without reading it	54	43
(P) Staff never/sometimes explains the purpose of a form before patients sign it	14	43
(P) Treatment staff has not discussed enough how cancer may affect patient emotionally	20	51
(P) Consulted with a social worker	20	51
(P) Consulted with a nutritionist	29	51
(P) Consulted with a physical therapist	15	51
(P) Consulted with a mental health counselor	2	50
(S) Clinic needs to improve **: <ul style="list-style-type: none"> • Confirming patient follow through after a referral is made • Assisting patients to find affordable medications and fill out applications, if needed • Asking patients if they would like help understanding their medical bills or insurance forms 	74 60 95	39 40 39

• Reviewing all written materials to check for readability and ease of understanding	76	41
• Using clinic forms designed to be easy to read	60	40
• Assessing patients non-medical needs and providing support or referrals	55	40
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Decision support	%	N
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(P) Treatment decisions were not made jointly by both patient and cancer treatment staff	24	51
(P) Patient never/sometimes had enough information to make treatment decisions	30	51
(P) Explanations about cancer are never/sometimes easy to understand	30	50
(P) Treatment staff never uses pictures, drawings, or models to explain things	41	51
(S) Clinic needs to improve ^{**} :		
• Staff awareness and sensitivity training about health literacy issues	90	41
• Staff uses clear oral communication techniques	37	41
• Working with patients to set priorities and develop action plans	60	40
• Suggesting patients to write down questions while waiting for appointments	51	39
• Asking patients if they need extra support and offering to work together with patients	35	40
• Creating an environment that encourages patients to ask questions	24	40
• Using teach-back method to assess understanding	70	41
• Using visual aids to enhance communication	88	41
• Avoiding medical jargon when communicating with patients	51	41

(P): Based on patient phone survey; (S): Based on staff self-administered survey

* Sample sizes vary due to missing responses to the patient and staff surveys.

** Reported percentages include responses that clinics need to improve, are not doing, or respondents were not sure the clinics were doing, or not applicable.