

Patient-Centered Communication in Cancer Care: The Role of the NCI's Cancer Information Service

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Abstract While patient-centered care and the reduction of suffering due to cancer are primary goals of the NCI, improvement in the delivery of patient-centered communication has been identified as a key NCI research priority. As research on patient-centered communication evolves, the potential contributions of programs such as the National Cancer Institute's (NCI) Cancer Information Service (CIS) cannot be overlooked. The purpose of this paper is to describe how the six core functions of patient-clinician communication described in the literature (fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions and enabling patient-self management) are embedded in the work of the CIS. The communication process used by the CIS to extend the patient-centered communication role of the clinician will be discussed. CIS training and quality management systems will be described. Lastly, suggestions for the role of CIS in future health information delivery and research will be explored.

Keywords Patient-centered communication · Health care · NCI · Cancer Information Service (CIS) · Patient-centered care · Clinician-patient communication

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Introduction

As new directions in health care systems evolve, patient-centered communication will assume an increasingly prominent role in achieving quality care for patients and their loved ones. Recent Institute of Medicine (IOM) reports provide recommendations for the redesign of twenty-first century health care and include a call for patient-centered care, which must encompass improved clinician–patient communication and primary attributes of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient (IOM Chasm, 2001 [1]; IOM, *Cancer Care for the Whole Patient*, 2008 [12]). The National Cancer Institute (NCI), in its effort to understand how a changing health care system could be redesigned to support the communication needs of patients, commissioned an extensive literature review and report. The resulting monograph, as described by [17], provides a conceptual framework for patient-centered communication in cancer care organized around six core functions in addition to associated communication behaviors for both the patient and the clinician [14]. The six core functions are defined as fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling self-management.

While the importance of good communication skills between the provider and the patient is well documented, the literature seldom describes the contributions made by other health information providers who support patient-centered communication. NCI's Cancer Information Service (CIS) is one such provider. The purpose of this paper is to describe how a federally funded cancer information program such as the CIS systematically incorporates the six core functions of clinician–patient communication described by Epstein and Street into its processes and outcomes in providing cancer information and education to the American public. It will also demonstrate how these core functions validate the established quality management and training systems of the CIS program in meeting the cancer

information needs of the patients and family members, heretofore referred to as “CIS callers,” who contact the CIS through 1-800-4-CANCER.

NCI’s Centerpiece for Patient Communication: The Cancer Information Service

The NCI is the nation’s lead federal agency for cancer information and research. NCI established the CIS in 1975 to provide accurate, up-to-date cancer information to all segments of the US population. Over its 36-year history as the first cancer information service program in the world, the CIS has become the premiere organization for providing cancer information to the public, a model for the delivery of cancer-related communication, and a laboratory for health communication research [10]. Highly trained English- and Spanish-speaking Information Specialists (IS) provide cancer information to patients and their family members who contact the CIS via telephone (1-800-4-CANCER), *LiveHelp* (an online instant messaging service), and by e-mail. The work of the CIS is grounded in the science of health communications and other models that have guided the development and refinement of its training, quality management processes, and research program.

The Role of the Information Specialist in Clinician–Patient Communication

Communication between clinicians and patients is a critical component of all clinical encounters. It is especially challenging in cancer care where the complexity of the medical information, the uncertainty regarding the disease, and the treatment outcomes add a potentially greater emotional dimension to the interaction [25]. Patient-centered communication has been defined as the skills and processes that foster eliciting, understanding, and validating the patient’s perspective; understanding the patient within his or her own psychological and social context; reaching a shared understanding of the patient’s diagnosis and treatment options; and helping the patient share decision-making power by offering him or her meaningful involvement in choices relating to his or her health [14]. Studies suggest that poor communication between clinicians and patients compromises not only the physician’s ability to deliver quality cancer care but also the patient’s satisfaction with that care [7]. Moreover, research in the area of patient-centered communication has demonstrated a positive relationship between the quality of physician–patient communication and a variety of outcomes including patient satisfaction, emotional health, symptom management, adherence to treatment, recall and understanding of information, accrual to clinical trials, better transition of patients from curative to palliative treatment, and decreased oncologist stress and burnout ([2, 9, 15, 22, 23, 27]).

At any given point along the cancer continuum, patients will interact with several providers or health systems, other than their physicians, who will likely impact their care as well as their health outcomes [4]. These providers and other health care systems can play a pivotal role in patient decision making by facilitating access to information and providing decision aids and other resources which can help the patient take an active role in making the most well-informed decisions [14]. For example, in 2009, the CIS telephone service received a total of 76,308 calls from individuals seeking additional cancer information. Of these calls, 20,814 (27.3%) were from patients and 23,892 (31.3%) were from a relative or friend of a diagnosed patient (Table 1). Callers to the CIS in 2009 most often requested information about breast, lung, prostate, colorectal, and cervical cancer. Caller characteristics have remained unchanged over many years, with a greater number of users being female, English-speaking, White, insured, with higher education, and with higher income [26].

The role of the IS in these interactions is to translate emerging and complex scientific information into information that cancer patients and family members can then apply to decision making regarding their own situation [24]. As shown in Table 2, the nature of these exchanges is wide ranging and covers a variety of cancer topics.

While the IS are continually supportive of the provider–patient relationship during the interaction, the confidential aspect of the CIS service provides a safe platform in which patients may ask questions that they may not yet be ready or willing to discuss with their own physician or family members. Previous research has indicated that increased information leads to increased patient involvement in decision making and greater satisfaction with care and treatment [26]. In a 2003 CIS National User Survey designed to measure satisfaction with its services, the vast majority of users responded that their knowledge had increased significantly (39%) or somewhat (34%) following their contact with the CIS [18].

Information Specialist Training and Quality Management

Increased attention is being given to the creation of training courses for oncologists and other physicians focused on the development of skills related to assessment, information exchange, delivering bad news, discussion of patient concerns, and missed opportunities for empathy [6, 7, 11, 16]. For example, *Oncotalk*, a program designed by Back et al. [7] with funding from NCI, is designed to improve oncology fellows’ communication skills with cancer patients. The NCI training program for IS, described below, incorporates those components most often cited by communication skills training experts as essential for effective training: a cognitive component, a behavioral component, and modeling [19].

Table 1 Caller profile—2009 ECRF data

Type of caller ^a	Number	Percentage
Patient		
Diagnosed, no treatment	5,061	6.6
Diagnosed, in treatment	7,099	9.3
Diagnosed, post-treatment	4,400	5.8
Diagnosed, treatment status unknown	1,821	2.4
Recurrence	2,433	3.2
Spouse, relative/friend of diagnosed patient	23,892	31.3
General public	22,579	29.6
Other (includes health professionals, media, organizations, etc.)	9,023	11.8

The Electronic Contact Record Form (ECRF) is NCI's data collection tool

^a For a comprehensive list of all categories, contact NCI's CIS

The cognitive component of IS training focuses on the provision of evidence-based information that allows for understanding the cancer continuum. Therefore, all IS must successfully complete training modules covering topics such as: the most common cancer sites; diagnosis, treatment, and side effects of treatment; and psychosocial issues including survivorship and end of life. Those elements of the curriculum that address communication and psychosocial aspects provide theory, techniques, and strategies designed to enhance the IS's ability to understand the patient's information requirements and address these needs in a clear, credible, and empathic manner. In addition, measures to ensure that the IS develop a clear sense of the performance expectations, highlighted later in this paper,

are woven throughout the training. The behavioral component of training focuses on the attainment of good communication skills and requires that the trainee have sufficient opportunities for practice through small group role plays, discussion, questions, and coaching. The modeling component begins with the IS observing and listening to an experienced IS engaged in authentic interactions. Extensive use of role plays with feedback by the participants and the facilitator are dispersed throughout the training and provide risk-free opportunities to practice communication skills and develop judgment. In addition, IS are required to listen to audio files which capture actual caller questions and concerns and also demonstrate how to establish rapport and trust, conduct a needs assessment, and exchange information. Trainees are

Table 2 Subject of interaction by patients, family members/friends and all callers—2009 ECRF data

	Patients (<i>n</i> =20,814) (%) ^b	Family (<i>n</i> =23,892) (%)	All callers ^a (<i>n</i> =76,308) (%)
Specific treatment information Includes clinical treatment trials, treatment/side effect management, complementary and alternative medicine	37.7	31.9	22.4
Cancer site information Includes metastasis, staging, patient care/follow up, prognosis, recurrence, statistics, symptoms, and cancer pain	25.1	26.7	22.9
Referrals to medical services Includes hospital/clinic/screening program, physician/second opinion	21.1	31.8	24.2
Support services Includes economic assistance, cancer agency, care delivery services, other support services	19.5	21.7	20.7
Psychosocial issues Includes support groups, coping, wellness after cancer, religious resources	7.1	7.3	5.6
Cancer screening and diagnosis Includes colonoscopy, screening/diagnostic mammograms, other screening/diagnostic tests and trials	3.2	2.4	10.9
Other Includes publications request, NCI information resources	2.9	2.7	4.7

Subject of interaction: For a comprehensive list of all categories, contact NCI's CIS

The Electronic Contact Record Form (ECRF) is NCI's data collection tool

^a All callers include all users of the service (e.g., general public, health professionals, etc.), including patients and family members/friends

^b Percent may exceed 100% because IS may code up to five subjects

guided through later parts of the training process by a group of specially selected mentors who shadow the trainee, coach, and provide ongoing feedback as the trainee engages in “real-time” interactions.

The CIS implements a robust quality assurance program to ensure that CIS callers receive information that meets their needs and expectations. The quality assurance program is built upon the key requirements of CIS callers and incorporates quality measures that ensure accurate, personalized information is communicated in a credible and empathetic manner. A list of key quality measures and indicators that serve as the foundation of the CIS quality assurance program are found in Table 3. Critical patient-centered communication processes that are essential to an effective dialogue with CIS callers are measured. These include: the extent to which an IS establishes a rapport with callers, their proficiency in engaging in dialogue (e.g., remembering information and weaving it into a conversation, allowing the patient to speak, acknowledging the difficulty of the situation), the use of active listening techniques

that enhance communication and understanding of key issues, and the extent to which empathy is conveyed appropriately.

Much of the success of the CIS rests on the continued efforts to examine, refine, and adapt its training and quality assurance model. The CIS Quality Assurance data reflect high scores in the quality measures described in Table 3 (Annual Quality Report Data, National Quality Assurance Program, NCI). In addition, results from the American Customer Satisfaction Index show a very high degree of satisfaction with services provided by the CIS, with the information and communication categories scoring highest among all categories [3]. In keeping with CIS expectations for high-quality interactions with callers and in line with NCI’s commitment to patient-centered communication, the current quality measures, indicators, and scoring methodology are in the process of revision.

The following section will highlight the role the IS play in extending the patient-centered communication role of the clinician with respect to the six core functions.

Table 3 Quality measures

Quality indicators	Expected behaviors
Quality measure 1: Information needs—Were the caller’s cancer information needs met? Was the information provided correct and tailored to the caller’s needs?	
Conducted appropriate needs assessment	Assessment was complete and tailored to caller’s needs and questions.
Provided correct information	Correct information was provided.
Provided complete information	Complete information provided to address caller’s needs and concerns, and other issues raised throughout call.
Tailored response to caller’s needs and questions	Response was personalized and tailored to caller’s needs and questions.
Checked caller’s understanding	Assessed to ensure caller’s needs were being met and information was understood throughout the call.
Explained technical terms	Technical terms were explained appropriately throughout call.
Provided information in organized manner	Information was communicated in an organized, logical manner, building on concepts and linking information together.
Quality measure 2: Delivery—Was the information conveyed in a professional, credible, empathetic manner?	
Facilitated rapport	Welcomed caller to service. Demonstrated willingness to help caller. Engaged in conversation with caller. Remembered important information told by caller and wove into conversation appropriately. Spoke at an even pace with caller, paying careful attention not to speak over caller or interrupt. Listened to caller; paid attention to important cues in conversation (e.g., silence, upset, tone). Checked back with caller within 5 minutes of hold.
Conveyed empathy	Made appropriate statements of empathy or support in response to caller’s comments/stated concerns. Acknowledged difficult situations.
Maintained professional tone	Spoke articulately. Used correct grammar. Used professional customer service language appropriately (e.g., thank you).
Demonstrated credibility	Correctly pronounced words and technical terms. Presented information with confident tone of voice.

Six Core Functions: Applicability to the CIS

Fostering Healing Relationships

Patient-centered cancer care is dependent on patient/family–clinician relationships that are characterized by trust, rapport, respect, and mutual understanding of roles as well as the clinician-related factors of self-awareness and well-being. In addition, healing relationships are more than provision of information and sharing of expertise; they also provide emotional support, guidance, and understanding [15]. While the CIS is not delivering patient care, these same principles guide the IS/caller interaction. The establishment of trust and rapport between the IS and the caller early in the interaction is paramount to effective information delivery and is considered a key quality indicator. The IS establishes rapport and trust with the caller by greeting them in a warm, caring manner, stating their willingness to help, and providing empathetic responses throughout the conversation. Callers frequently share distressing scenarios with the IS, ranging from experiences with severe side effects from treatment to physical, cognitive, and/or emotional problems resulting from the disease itself. Although they are not counselors, IS are encouraged to allow the caller to discuss concerns without interrupting, acknowledge that the caller may be feeling distraught, confused, and overwhelmed, and to communicate sensitivity using appropriate “normalizing” and validating statements. Experienced IS are skilled in using clarifying techniques that ensure they understand correctly what is being shared while simultaneously acknowledging and addressing the concern with compassion. Studies indicate that expressing empathy can be taught and that empathic statements such as “it sounds like this is difficult for you” or “it is normal to have these feelings” can be brief but powerful [21]. IS are reminded about “missed opportunities” for empathetic responses. Providing empathy early on in the discussion and at intervals throughout the encounter are key to the IS establishing trust and rapport with the caller as well as exploring the caller’s needs and concerns.

Exchanging Information

Cancer patients and their families want information about the disease, diagnosis, treatment, prognosis, psychosocial aspects, and end-of-life care. Clinicians need to respond adequately to the information needs of the patient not only to help the patient gain knowledge about his or her illness but also to develop a strong patient–clinician relationship, to assist patients with decision making, and to reduce patients’ uncertainty [14]. Despite this, findings from the 2007 Health Information National Trends Survey (HINTS) survey show that 14% of patients reported never/sometimes being given a chance to ask all their health-related questions

at their visit with the clinician and that 13% of respondents said they never/sometimes understood the things they needed to do to take care of their health [5] (HINTS Conference). Unfortunately, the abbreviated time slot afforded in most clinical encounters is simply not adequate to provide all the information patients may need [17].

These findings speak to the need for information experts, such as the CIS, to support and enhance the clinician’s role as an information provider and to act as a partner in the process of exchanging information. The wide variety of evidence-based educational resources available to the IS, along with their expertise in selecting the most appropriate resources, positions them to play a key role in helping the patient understand their disease, reviewing treatment options, formulating questions for their physicians, learning how to get a second opinion, or finding resources to aid with financial assistance. National 2003 CIS User Survey data indicate that 28% of users had discussed the information received from CIS with a health care professional, and another 43% planned to do so. Among those who had already discussed CIS information with a health care professional, 56% said that the information helped them significantly and about half said their contact with CIS resulted in participation in a clinical trial [18]. As a result of speaking to an IS, users report enhanced skills in communicating with health care professionals [18].

The information exchange between the IS and the caller ensures that the caller’s concerns are elicited and explanations are understood. IS are expected to continuously adapt the amount and complexity of information to the comprehension level and needs of the caller who is seeking it. This is a skill, as pointed out by [13], which may be beyond the ability of many experienced clinicians. For example, the patient-centered communication skills suggested by Epstein and Street [14] for helping clinicians respond to patients who are having difficulty with treatment decision making, such as asking patients about their information needs, providing clear explanations, avoiding medical jargon, and checking for understanding, are the same skills expected of the IS in their interactions with callers. Use of clarifying phrases and open-ended questions such as “tell me a bit more about your situation and what the doctor has told you” allows the IS to gather relevant information early in the interaction, to identify the most appropriate resources, and to tailor the information to the caller’s needs. Arora [4] notes that assessment of patient understanding may be one of the least likely conducted activities on the part of clinicians; however, it is the cornerstone of the interaction between callers and IS. Patients often report feeling upset or overwhelmed after they hear the devastating news of a cancer diagnosis; such anxiety makes assimilation and recall of further information difficult [14]. For this reason, the IS regularly checks the caller’s understanding by restating and summarizing information to

ensure that the caller understands and remembers the information for discussion in follow-up clinical visits.

Responding to Emotions

A diagnosis of cancer is most often accompanied by a range of emotions including fear, anger, sadness, and even clinical depression and anxiety disorders. Patients who are unable to resolve their emotional turmoil frequently experience difficulties in decision making and in meeting the demands of their cancer treatments [17]. Clinicians often miss opportunities to respond to patients' emotional concerns because they fail to recognize the cues provided by the patient, are unclear about how to respond to them, or believe that there is insufficient time in the clinical encounter to address emotions [8, 21]

While addressing the psychosocial needs of the caller is not the primary responsibility of the IS, callers do share their emotions and feelings during most interactions, and IS are expected to convey reassurance and support. Because the manner in which the information is presented and the quality of the information provided has a significant effect on patients' emotions [14], IS are reminded that providing clear information, discussing questions and feelings, encouraging involvement in decision making, and being reassuring are among the communication approaches that may be helpful in reducing patient's anxiety [26]. A caller may say "I feel like my friends and family don't really understand what I'm going through," thus opening the discussion about support groups where patients may connect with others in similar situations to hear experiences, share advice, and learn about new approaches.

Effective communication on the part of clinicians requires self-awareness and self-monitoring in order to identify patients' perspectives and distinguish them from their own [14]. Similarly, the CIS has found that IS who experience burnout cannot display the necessary empathy to do an effective job. Consistent with the literature concerning clinicians, it is imperative that IS develop/maintain self-awareness of their emotions and acknowledge and work toward managing their own stress and emotions effectively. This is an important aspect of training and remains an essential component in the professional development of the IS. Ongoing coaching by trainers and supervisors, peer support, and continuing education with subject matter experts help minimize the potential burnout that can be associated with the role.

Managing Uncertainty

Uncertainty is a persistent component of chronic illness due to the unpredictable and inconsistent symptoms, constant ques-

tions about recurrence or exacerbation, and an unknown future [20]. Patient-centered communication should not only reduce uncertainty but should also help patients with cancer manage their uncertainty [4]. Epstein and Street [14] remind us that health care systems can greatly assist the management of this uncertainty by providing education, resources, and referrals, thereby empowering the patient. The CIS is one of the systems that best illustrates this concept.

Patients who contact the CIS express a wide range of doubt and uncertainty concerning treatment effectiveness, long-term effects, insurance coverage, prognosis, and what their future will entail. This is especially true among Spanish-speaking callers of the CIS. Close to half of all interactions in Spanish (42%) cite "coping" as the subject of interaction and conversations, with bilingual IS revealing that many Spanish-speaking callers express having difficulty communicating with health care providers and are particularly grateful to speak with an IS who takes the time to review confusing and unfamiliar information.

The knowledgeable and empathetic approach of the IS coupled with the evidence-based NCI resources used to respond to questions and concerns are key to helping callers manage uncertainty. For example, many callers contact the CIS requesting information about survival "statistics" for their type and stage of cancer. Not surprisingly, most callers requesting this information have difficulty understanding the implications of these statistics for their own individual situation. When the prognosis is poor or not clear-cut, the IS must handle the caller's questions in a manner that is factual yet sensitive, empathetic, and tailored to the caller's situation and that also provides hope. The IS stresses to the caller that statistics are not meant to apply to an individual situation but to populations of patients and should be discussed with his or her physician. Using phrases such as "This could be difficult information to hear; how are you doing?" or "Would you like me to stop here or go on?" help to acknowledge the difficulty the caller may be experiencing and allows the caller to set the pace of the discussion.

Making Decisions

Decision making is integral to all points along the cancer continuum. Implementing informed decision making is difficult because the present health care system is not equipped to inform patients in a manner that is timely or easily understood, nor does it encourage patients to consider consequences, ask questions, clarify values, or express preferences [29]. Findings from the 2007 HINTS indicate that 21% of respondents were never/sometimes involved in decisions as much as they wanted (NCI [5] Conference abstract).

Many of the decisions faced by callers who contact the CIS involve deciding on a treatment option, considering a clinical trial, selecting a treatment facility, getting a second opinion, and managing treatment side effects. IS play a key

role in supporting informed decision making by providing evidence-based information that helps the caller understand all available treatment options and form their own impression regarding one approach over another. For example, when the caller asks several complex questions about treatment, the IS listens to and records the questions and then outlines how each will be addressed, comparable to [14] strategy of “setting an explicit agenda.” The IS then validates the overwhelming task of sorting out information by stating, “Trying to understand so much information in a short period of time is hard. Let’s talk about what information you think will help you in making a treatment decision.” The IS endorses the caller’s participation in the discussion with the clinician by stating, “I can help you think about questions you may want to ask your doctor, review the treatment options with you, and then send you the information so that you may review it further and bring it to your physician.” In this way, the IS helps the caller to organize their thoughts and questions which will assist them in setting an agenda for discussion about treatment with their clinician. When a patient progresses along the cancer continuum toward the end of life, questions often shift to requesting information that will inform decision making about disease stabilization and/or comfort care. Providing information regarding palliative care and available support resources in a neutral, non-judgmental, and empathetic manner is crucial to helping the caller feel supported.

In helping callers work through the numerous and varied decisions that they are faced with, the IS act as highly skilled knowledge brokers, or what Woolf refers to as “decision counselors.” This is a professional who offers certain qualities that clinicians may lack, namely, a talent for assembling the best educational resources for patients without the interference of competing agendas and specialty bias and the expertise to guide patients in recognizing and applying personal preferences [29]. When asked, 67% of CIS respondents diagnosed with cancer reported feeling more confident in their ability to actively participate in their treatment decisions after their interaction with an IS. After contact with the CIS and discussion with a health care professional, more than half stated the CIS information helped them significantly and another 31% said it helped somewhat [18].

Enabling Patient Self-Management

Facilitating patients’ ability to be active, capable participants in their own clinical visits and decision making and encouraging the development of self-care skills necessary for managing everyday health issues is an integral part of communication in cancer care [28]. Findings from the 2007 HINTS indicate that 13% of respondents never/sometimes understood the things they needed to do to take care of their health (Arora, NCI 2009 Conference Abstract). Self-

management in cancer care includes many components, but three are particularly important: advocating and navigating, supporting patient autonomy, and providing guidance, skills, and access to resources [14].

The CIS promotes patient self-management by empowering callers to advocate for themselves and by enhancing their ability to navigate the complex array of information and health care systems in which they are immersed. For example, IS assist callers in identifying hospitals that provide quality cancer care, understanding how to obtain a second opinion, and encouraging them to consider how other health care team members such as a nurse, social worker, or nutritionist can be resourceful. For those requesting information about financial assistance to cover the cost of treatment or transportation, the IS provides referrals to state and national organizations that may provide tangible support services such as financial, legal, or advocacy assistance.

With respect to the critical issues of patient autonomy and guidance in accessing resources, IS regularly reinforce the importance of returning to clinical visits with specific questions and writing down the clinicians’ responses so as not to forget what has been said (a common problem for overwhelmed and anxious patients). In addition, the IS provide information on managing treatment side effects such as fatigue, pain, and depression. Other issues addressed may include the transition from hospital to home or from one phase of care to another, handling nutritional deficits, problems while on treatment, or how to cope with grief and bereavement after a significant loss.

Conclusion

Improving clinician–patient communication is one of the many recommendations for restructuring health care for the twenty-first century (IOM, 2001). The potential contributions of health systems such as the CIS to this restructuring are significant and should be considered in future discussions calling for improved patient-centered care. First, the CIS has mastered the science of providing patients with evidence-based information and translating research findings and recommendations across a variety of channels, all of which augment and support patient–clinician interactions. Second, its focus on patient-centered communication, its pedagogical training methods, and its emphasis on quality assurance make CIS a model for those developing curricula around patient-centered communication. Third, the CIS experience in preparing non-clinicians as patient communication experts speaks to its place as a valuable member of the multidisciplinary health care team of the future. Lastly, the CIS has been a valuable partner for researchers. Eggly et al. [13] note that future research on clinician communication may benefit from questions posed

by patients themselves. The CIS is well positioned to inform such approaches. Clinicians should feel confident about the role that the CIS can play in supporting and fostering communication between them and their patients.

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