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Article type : Original Article

What is Empathy?
Oncology Patient Perspectives on Empathic Clinician Behaviors

(Running Head: Oncology Patient Perspectives on Empathy)

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This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1002/CNCR.33834](https://doi.org/10.1002/CNCR.33834)

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2 Running Head: Oncology Patient Perspectives on Empathy

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Funding Statement: Tom and Elizabeth Long Research Award, The University of North Carolina at Chapel Hill Honors Program (Dubey); Ahdieh Family Scholarship in Health Policy and Management, The University of North Carolina at Chapel Hill, Gillings School of Global Public Health (Dubey)

Conflict of Interest: The authors have no conflict of interests to declare.

Author Contributions: Justin Sanders: Conceptualization, methodology, formal analysis, resources, visualization, writing – original draft; Manisha Dubey: data curation, formal analysis, funding acquisition, investigation, project administration, visualization, writing – original draft; Judith Hall: Conceptualization, methodology, formal analysis, writing – review and editing; Hannah Catzen: project administration, writing – review and editing; Danielle Blanch-Hartigan: supervision, writing – review and editing; Rachel Schwartz: methodology, formal analysis, writing – review and editing.

Acknowledgements: The authors wish to acknowledge Morris Weinberger, PhD at the Gillings School of Public Health for his support in coordinating the participation in our summer research assistant program by Ms. Dubey. We would also like to acknowledge the patients who participated in our survey for their generous contribution to improving patient care.

Lay summary: Oncology patient responses to an open-ended question about empathic clinician behavior revealed insights into a variety of behaviors that are perceived as demonstrative of empathy. These include behaviors that imply sensitivity to the clinician-patient relationship, such as listening and understanding, and attention to the whole person. Participants valued caring communication and demeanor and clinician accessibility. Perspective-taking was not common among answers. Many existing measures of clinical care quality do not include the behaviors

3 Running Head: Oncology Patient Perspectives on Empathy

cited by patients as empathic. These results can inform efforts to refine quality measures of empathy-associated behaviors in clinical practice. Cancer centers can employ skills training to improve elements of communication.

Precis for Table of Contents: Oncology patients' open-ended responses reveal new insights into clinician behaviors and qualities that convey empathy. Results suggest opportunities to inform empathy measure refinement and clinician training.

ABSTRACT

Background: Oncology patients and physicians value empathy because of its association with improved health outcomes. Common measures of empathy lack consistency and were developed without direct input from patients. Because of their intense engagement with healthcare systems, oncology patients may have unique perspectives on what behaviors signal empathy in a clinical setting.

Methods: As part of a cross-sectional study of patients at an academic northeastern U.S. cancer center to examine patients' perceptions of clinician behaviors that signal empathy, we solicited up to ten free-text responses to an open-ended question about what clinician behaviors define empathy. We applied latent content analysis to derive categories and sub-categories of patient-identified empathic behaviors.

Results: We categorized open-ended responses from 89 oncology patients into 5 categories representing 14 themes. These categories were relationship sensitivity, focus on the whole person, communication, clinician attributes, and institutional resources and care processes. Frequently represented themes included listening, understanding, and attention to emotions and what matters most align with existing measures of empathy; behaviors that are not well represented among existing measures included qualities of information sharing and other communication elements. They also associated clinician demeanor, accessibility, and competence with empathy.

Conclusion: Oncology patients' perspectives on empathy highlight clinician behaviors and attributes that may help refine patient experience measures and may be adopted by clinicians and cancer centers to enhance patient care and outcomes. High-quality communication skills training

4 **Running Head: Oncology Patient Perspectives on Empathy**

can promote active listening and paying attention to the whole person. A system-level focus on delivering empathic care may improve patient experience and outcomes.

Keywords: Empathy, Oncology, Qualitative, Communication, Quality Improvement

Text Pages: 16

Tables: 2

Figures: 0

Supporting Files: 2

INTRODUCTION:

Empathy is a widely and increasingly used term in society and in healthcare. Healthcare systems advertise and promote empathy in clinical care delivery, and medical education has developed specific curricula to increase empathy among students.^{1,2} A search of the term “empathy” in clinical research indexed on PubMed yields nearly 20,000 studies in the past five years. The ubiquity of the concept of empathy in healthcare is not surprising given its association with patient-centered care³⁻⁵ and important healthcare outcomes, including reduced severity and duration of the common cold,⁶ good chronic condition management,^{7,8} and lower PTSD symptoms after life-threatening medical emergencies.⁹

In oncology, there is a well-established focus on empathy as an important construct of care delivery.^{10,11} Empathic care holds particular importance for patients with cancer, who experience significant emotional distress, including feelings of fear, worry, anxiety, anger, and sadness.¹²⁻¹⁴ Cancer patients’ ratings of empathy are associated with greater patient satisfaction, increased self-efficacy, and reduced emotional distress following consultation.¹⁵⁻¹⁷

Empathy is ill-defined in both research and practice. Analysis of a sample of 489 studies on measuring “empathy” from 2001 to 2017 revealed considerable inconsistency in the measurement and definition of empathy.¹⁸ Potential definitions include: general sympathy or prosocial concern for others; a vicarious or shared emotional experience; an ability to recognize or respond to another’s emotions or perspective; or some combination of these.

Missing in this prolific use of the term empathy is the patient perspective, especially in clinical care. To our knowledge, no studies have directly asked patients to reflect on empathy or the

5 Running Head: Oncology Patient Perspectives on Empathy

clinical behaviors that convey it. In studies where patients directly identified empathy as an important factor for successful medical consultation, what “empathy” meant to those patients was not explored.^{19,20} Other qualitative studies have explored patient perspectives on “caring” and “un-caring” behaviors²¹ and others have asked patients about their communication experiences or preferences, but do not focus on explicitly on empathy.^{22,23}

Clinical empathy training currently includes a wide range of elements,²⁴ such as perspective taking, nonverbal communication, genuine interest, active listening, and demonstrated compassion.^{6,25} Additionally, widely used measures that are said to measure clinical empathy from the patient’s perspective, including the Consultation and Relational Empathy Measure (CARE)⁵ and the Jefferson Scale of Patient Perceptions of Physician Empathy (JSPPPE),²⁵ do not ask patients which behaviors represent “empathy” to them, and assume an unsubstantiated equivalency between a generally good provider consultation and empathy. They were primarily developed and refined through primary care clinician feedback without directly accounting for patient perspectives on empathy.^{26,27}

To inform clinicians of behaviors that cancer patients view as empathic and to ground future measurement of empathy in the subjective experience of patients, it is essential to understand what empathy means to cancer patients and which clinician behaviors patients believe convey empathy. We conducted a qualitative study to elicit cancer patients’ descriptions of clinician behaviors comprising empathy.

METHODS:

Survey development

We developed and administered a survey to elicit cancer patients’ personal definitions of empathy in the context of medical care. In the first part of the survey, patients were asked in a free-response format to list up to 10 clinician behaviors that they would define as empathic. In the second part, patients rated 49 hypothetical clinician behaviors for how well they fit their personal definition of clinician empathy; these quantitative results are described elsewhere.²⁸ Patients were instructed to consider only their personal definition of empathy rather than the general desirability of a given behavior, and also to consider the behaviors hypothetically (i.e. not to rate their own clinicians).

6 Running Head: Oncology Patient Perspectives on Empathy

Demographic questions assessed patients' age, race/ethnicity, gender, subjective English fluency, and self-rated health and functional status.²⁹ Study data were collected and managed using REDCap electronic data capture tools hosted at Partners HealthCare.³⁰ Patients had the option of taking the survey on an iPad, on their own mobile device, or on paper; in some cases, the research assistant transcribed their spoken answers.

The Dana Farber Cancer Institute/Harvard Cancer Center Office for Human Subjects Research and the Committee on Human Subject Research Protection at Northeastern University reviewed the study protocol and deemed it exempt from human subjects review.

Participant recruitment

We recruited patients (N=89) from Dana-Farber Cancer Institute (Boston, MA) outpatient clinics and Dana-Farber Brigham and Women's Cancer Center at Brigham and Women's Hospital (Boston, MA) inpatient floors over a 3-week period during the summer of 2019. With the permission of nursing staff, patients were approached by a research assistant if they were over the age of 18, spoke English, and were physically able to participate. After describing the study and obtaining verbal consent, the research assistant read aloud and clarified the survey instructions. Patients who said they were not familiar with the word empathy (n=4) were excluded.

Qualitative data analysis

Three members of the research team (JS, MD, RS) independently hand-coded the free-response items, which ranged in length from one word to one sentence, using an inductive latent content analysis to identify themes.^{31,32} Two coders, one a palliative care clinician (JS) and the other with a doctorate in communications research (RS), had extensive prior experience with qualitative analysis. They provided training and iterative support to a third coder (MD), a research assistant and public health undergraduate student. They each generated codes separately and then convened to identify the most salient categories. After meeting, these authors developed an initial codebook. Two of the authors (MD, RS) then refined the codebook by applying it to open-ended responses in a new round of coding. Some answers received multiple codes when we inferred multiple meanings. After the two coders independently re-coded, JS adjudicated

7 **Running Head: Oncology Patient Perspectives on Empathy**

discrepancies in responses and reconvened the team to arrive at an agreed-upon coding and to revise the codebook again to ensure all data were appropriately coded. Any remaining disagreements were adjudicated by a fourth author (JAH). The final coding guide is published as Supplementary Material Appendix A. Many patients offered more than one behavior that received the same code. For our analysis, a given code was counted only once per patient to ensure that patients who were more forthcoming with their responses were not disproportionately represented. Specific coding categories were organized into superordinate categories for ease of interpretation based on related themes.

RESULTS:

Patient Characteristics

Of 158 patients approached, 4 were unfamiliar with the term empathy and therefore excluded, and 107 agreed to take the survey (69.5%). We further excluded 11 who did not self-identify as having cancer and 7 who provided illegible written responses. We analyzed data from 89 patients (57.7% of all approached; see Table 1 for patient characteristics). Patients were recruited from chemotherapy infusion rooms in clinics treating hematologic cancers like leukemia and lymphoma (60%), and solid tumor cancers like breast and genitourinary, gynecologic, thoracic, neurologic, and head and neck cancers (40%). Patients had a mean age of 60 and were 63% female, 85% white, and 95% native English speakers.

Thematic categories of clinician behavior

While able to list up to 10 clinician behaviors, patients listed an average of 3.8 (335 responses altogether), from which 14 themes emerged. We organized these into 5 categories (see Table 2 for response frequencies and example quotations and Supplementary Table 1 for a complete response list).

Category 1: Relationship sensitivity

Patients frequently described behaviors that suggested clinicians' sensitivity to their lives or illness based on their relationship. Thirty percent (n=101) of responses fell into this category. For example, patients described the clinician as "sensitive to my situation" and provided "support."

8 Running Head: Oncology Patient Perspectives on Empathy

Patients frequently cited the act of *listening*, such as “listens to concerns” and “listens carefully to the patient.” Another theme in this category included descriptions of demonstrating *caring/concern/compassion/sympathy* for their patients, such as “showed interest and concern and took me as an urgent priority” and “caring/focusing on me when asking personal questions.” Patients also used the word *respect* as a marker of empathy, such as when clinicians “respected my time” and “respected giving explanations when asked.”

Category 2: Focus on the whole person

Out of the 335 responses, 27% (n=90) also concerned a clinician’s focus on the whole person as a sign of empathy. Patients described behaviors and situations in which clinicians paid special attention to those aspects of patients’ lives that fall outside the strictly clinical. One theme in this category was *attention to what matters most* to the patients, in which clinicians demonstrated particular attention to details of the patient’s life, such as “asking the patient about how I’m handling my illness in all aspects of my life. Jobs, family, etc.” and “remembers details from past conversations and visits.” Patients described a clinician’s particular *attention to feelings or emotions* of the patient, such as “acknowledges emotional aspects of patient behavior” and “when doctors validate my negative emotions instead of trying to convince me otherwise before I am ready.” Some explicitly used the word *understanding* to describe a clinician’s awareness of circumstances that influence patient positions and actions, such as “understanding past problems and how they relate to current events” and “understanding where the patient comes from.”

Category 3: Communication

Patient responses also included explicit forms of verbal and nonverbal communication as demonstrating empathy (22%, n=75). Most commonly, they described qualities of *information sharing* by clinicians, such as comprehensiveness, simplicity, and bidirectionality. Examples include “discussion back and forth” and “when my doctor takes time to explain everything to me without making me feel dumb or like I cannot understand what he is saying.” Patients described what we called *procedural communication*, such as comments by clinicians that solicit the need for additional support or address harm in a procedure: for example, “asking you if there is anything else they could do for you” and “apologizing if they feel they’ve hurt me while prepping me for infusion.” *Nonverbal communication* that signaled empathy included “body

9 Running Head: Oncology Patient Perspectives on Empathy

language that shows engagement and investment: leaning in, smiling or looking sympathetic, direct eye contact” and “nodding as if hearing and understanding.”

Category 4: Clinician attributes

Patient responses (17%, n=56) include clinician qualities and attributes that they believed conveyed empathy. Some included what might be called clinician *demeanor*, the subjective, sometimes intangible assessments of a clinician’s general comportment, such as “truthful and kind” and “being friendly and upbeat or sympathetic as needed.” They cited clinician *accessibility*, typically outside the context of a normal visit, such as “making certain I know how to reach them during emergencies” and “being available online or by phone to answer questions.” Patients referred to clinicians’ abilities to do something with *competence or expertise*, such as “being able to assimilate effects of old treatments that haven’t worked” and “Follow up. Do what they say they’ll do.”

Category 5: Institutional resources and care process

A small number of responses contain descriptions of institutional resources and care processes that helped patients feel better cared for as indicative of empathy (4%, n=13). Notable examples include “teamwork between doctors,” “being on time,” “having tissues close by,” and “always having the same nurse for infusion.”

DISCUSSION:

Despite growing interest in empathy in the clinical context and existing scales that purport to measure it, no prior studies have examined individual patient’s opinions about the clinician behaviors and qualities that they perceive as empathic. We asked patients actively undergoing cancer treatment to tell us, in their own words, what behaviors they believe convey clinician empathy. Qualitative analysis identified 14 themes, organized into 5 categories, which frame patient-described behaviors and qualities that they believe demonstrate empathy by clinicians. We called these categories relationship sensitivity, focus on the whole person, communication, clinician attributes, and institutional resources and care processes.

10 Running Head: Oncology Patient Perspectives on Empathy

Our findings align with those of one prior study which performed a secondary analysis on focus-group data from patients with chronic pain and major depression for their perspectives on empathy.³³ The authors describe two “sub-concepts” of empathic interaction: empathic listening and empathic action. Patient descriptions of being listened to, understood, and valued comprised the former. The latter is not clearly defined. They also highlight characterizations of empathy by focus group participants, notably: friendliness, openness, and helpfulness. Though not focused on specific clinician behaviors, the findings accord with our own analysis, in particular the ways in which patients valued listening, understanding, and clinician demeanor. One study identified “tips” for doctors to improve the patient-centeredness of consultations. Some of these, like non-verbal attention and personal attention, overlap with our findings.¹⁹ Another tip, “show compassion, be empathic,” highlights in its lack of specificity the potential value of the findings presented here.

Our findings have some conceptual overlap with constructs assessed by commonly utilized empathy instruments. The 10-item CARE instrument includes aspects of clinician empathy that we also identified, such as intent listening, interest in the patient as a whole person, understanding of concerns, demonstration of care and compassion, and clarity of explanations. The 5-item JSPPPE similarly includes items that overlap with our findings, including understanding emotions, feelings, and concerns; concern about patients and their families; asking about what is happening in daily life; and seeing things from the patient’s perspective. Items in the CARE and JSPPPE seem to overlap specifically with the category of relationship sensitivity in our patient responses, which included items such as listening, and demonstrating caring, concern, sympathy, and compassion.

Our assessment of empathy brought unique findings regarding several specific verbal and nonverbal communication practices that cancer patients consider empathic, i.e. what is said and how. However routine in clinical practice, patients viewed verbal communication practices such as asking for additional questions or apologizing for procedure-related pain as demonstrative of empathy. Patients also emphasized the style and quality of information sharing during clinical encounters in their definitions of empathy, using words like “comprehensive,” “honest,” and “realistically reassuring.” While the JSPPPE assesses the degree to which a doctor “asks about what is happening in daily life,” and the CARE survey assess the degree to which the clinician

11 Running Head: Oncology Patient Perspectives on Empathy

“explained things clearly,” neither captures the range of communication behaviors we elicited that appear to affect assessment of perceived clinician empathy. Patients also identified clinician personal attributes and qualities that they felt signaled clinician empathy. These were not actions, but rather their outward behavior or bearing, i.e. demeanor, such as “kindness” and “patience,” and phrases such as “having a sense of humor” and “feeling like the doctor isn’t in a rush to move on to other things.” These qualities seem related to, but more specific than, what the CARE survey assesses when asking how the doctor was at “making you feel at ease.”

Some findings were more surprising and lacked correlates in widely used empathy measures. Some patients cited accessibility, e.g. reachability outside of regular clinic hours, and competency, such as clinical skill, as part of their personal definitions of empathy. One could imagine that a clinician’s availability to a patient represents sensitivity to the daily struggles of undergoing cancer treatment. Although standard definitions of clinical empathy may not include signs of competency, patients may view skill and conscientious task performance as an indicator of positive regard. The distinction between “task” and “caring” behaviors is murky, because task functions may make the patient feel cared for and respected.³⁴ Similarly, we were surprised by patient answers that identified institutional resources and care processes, e.g., “amenities like lunch or acupuncture” or “always having the same nurse for infusion,” as indicative of empathy. Again, patients may perceive a supportive overall care environment as indicative of individual clinicians’ attributes, particularly empathy. Finally, “sympathy” was listed as a behavior demonstrative of empathy by some respondents. The relationship between sympathy and empathy, as perceived by patients, deserves more exploration. While these concepts may be related in the minds of patients and clinicians,³⁵ some literature suggests that sympathy may be more akin to pity, unwanted, and detached from recipients’ emotional needs.³⁶

Implications for cancer care

These qualitative findings align well in some cases with constructs measured by existing instruments and also suggest behaviors that clinicians may adopt or emphasize to foster empathic oncology practice. Patients view good care as empathic care, and view behaviors that indicate and contribute to a caring environment as empathic. While these findings are hypothesis-generating and suggest and can inform future efforts to refine measures of patient experience,

12 Running Head: Oncology Patient Perspectives on Empathy

they imply that oncology clinicians should give attention not only to the content of their consultations, but to specific communication practices and behaviors that enhance a patient's sense of being heard and understood and that have long been advocated among those who teach communication skills. These include active listening, asking patients about what matters in their lives and how it may be affected by their illness or treatment, and paying specific attention to emotions. These are skills that can be developed,³⁷⁻⁴⁰ and structured tools exist to support communication that meets these objectives.⁴¹ Less previously clear was the degree to which patients see accessibility as a sign of empathy. Oncologists, like other physicians, must maintain personal and professional boundaries that limit their accessibility. However, cancer centers should work to create processes that support patients' perceptions that clinicians, or members of their teams, are accessible as much as possible. Similarly, while oncologists face demands to improve productivity, the degree to which they can cultivate an outward appearance of being unrushed, kind, and thorough, may enhance the degree to which patients feel their clinician is empathic. Finally, though certain resources and care processes may be out of an individual clinician's control, our findings suggest that every effort to create an overall supportive clinical environment may translate to patients perceiving individual clinicians as more empathic.

Limitations

Our study took place at a single academic cancer center with a predominantly White patient sample. This limits the applicability of our findings to BIPOC or other under-represented groups, whose voices and experiences are not represented in this work. Given the long history and current problem of discrimination in medical communication, understanding what empathy means to BIPOC patients is vital to improving their care experience and increasing culturally sensitive communication training for clinicians.⁴²⁻⁴⁶ Additionally, cancer patients may think of empathy differently than the general patient population. Their frequent and intense interactions with the medical system may heighten their awareness to a broader scope of clinician behaviors to categorize as empathic and sensitize them to the impact of behaviors.

CONCLUSION

Oncology patients' views on clinician empathy should be used to inform verbal and non-verbal clinical communication practices. The perspectives captured in the current study highlight key behaviors, attributes, and institutional resources that may 1) inform future refinement of quality

13 Running Head: Oncology Patient Perspectives on Empathy

measures of patient experience, and 2) be adopted and prioritized to enhance the caring environment and improve patient outcomes. They may also guide further research to link patient-perceived empathic behaviors to patient outcomes. Most important among these appear to be active listening and paying attention to the whole person, both of which can be actualized through high-quality communication. System-level approaches to delivering such communication, e.g. training, coaching, and quality assurance, can enhance the degree to which patients feel their care is empathic and of the highest quality.

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14 **Running Head: Oncology Patient Perspectives on Empathy**

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15 **Running Head: Oncology Patient Perspectives on Empathy**

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16 Running Head: Oncology Patient Perspectives on Empathy

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17 Running Head: Oncology Patient Perspectives on Empathy

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18 Running Head: Oncology Patient Perspectives on Empathy

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Tables and Figures

Table 1. Patient demographics*, N=89

Characteristic	N (%)
Female Gender	55 (63.2)
Age (mean, range)	60 (21-87)
Race/Ethnicity	
White	76 (85.4)

19 Running Head: Oncology Patient Perspectives on Empathy

Black/African-American	2 (2.2)
Asian	1 (1.1)
Native American/Pacific Islander	2 (2.2)
Hispanic/Latino	2 (2.2)
Native English speaker	80 (95.2)
ECOG (performance status)**	
0	30 (36.6)
1	38 (46.3)
2	9 (11.0)
3	5 (6.1)
Cancer diagnosis	
Hematologic	53 (60.0)
Solid Tumor	36 (40.4)
Admitted to the hospital in prior 12 months	
Yes	33 (45.2)
No	40 (54.8)

* Some demographic categories report incomplete data because of lack of participant information

** Describes cancer patients' level of functioning in terms of ability to perform daily activities

Table 2. Cancer Patients' Descriptions and Frequencies of Behaviors Deemed Empathic in Clinicians (N = 89 patients)

Categories / subcategories	Frequency (N=335)*	Representative examples
Relationship sensitivity (N=101, 30%)		
General	30	"Sensitive to my situation" "Tries to put themselves in my position" "Support"
Listening	43	"Listens to concerns" "Listens attentively" "Helping by providing audience to my questions"
Caring / compassion	21	"Showed interest and concern and took me as an urgent priority" "Caring/focusing on me when asking personal questions" "Demonstration of concern for the patient"
Respect	7	"Respected my time" "Respected-giving explanations when asked" "I think a doctor is empathetic when they are respectful of your diagnosis"
Focus on the whole person (N=90, 27%)		
Attention to what matters most to me	40	"Asking the patient about how I'm handling my illness in all aspects of my life. Job, family, etc." "Did everything possible to make it easier for me" "Remembers details from past conversations and visits"
Understanding	20	"Taking time to understand patients concerns as they relate to their lives" "Understanding past problems and how they relate to current events" "Understanding where the patient comes from"

21 Running Head: Oncology Patient Perspectives on Empathy

Attention to my emotions	30	<p>“When doctors validate my negative emotions instead of trying to convince me otherwise before I am ready”</p> <p>“Acknowledges emotional aspects of patient behavior”</p> <p>“Agree with patients emotions but not interfere with the patients care”</p>
Communication (N=75, 22%)		
Nonverbal communication	25	<p>“Body language that shows engagement and investment: leaning in, smiling or looking sympathetic, direct eye contact”</p> <p>“Facial expressions, hand gestures, mannerisms”</p> <p>“Nodding as if hearing and understanding”</p>
Procedural communication	16	<p>“Asking you if there is anything else they could do for you”</p> <p>“When doctors use my words and reflect what I say”</p> <p>“Apologizing if they feel they’ve hurt me while prepping me for infusion”</p>
Information sharing	34	<p>“Shares test result findings in a comprehensive way”</p> <p>“Discussion back and forth”</p> <p>“When my doctor takes time to explain everything to me without making me feel dumb or like I cannot understand what he is saying”</p>
Clinician attributes (N=56, 17%)		
Access	13	<p>“Communication/making certain I know how to reach them during emergencies”</p> <p>“Being available at any time if questions arise”</p> <p>“Being available online or by phone to answer questions”</p>
Competence	9	<p>“Being able to assimilate effects of old treatments that have not worked”</p> <p>“Follow up. Do what they say they’ll do”</p>
Demeanor	34	<p>“Nonjudgmental”</p> <p>“Is truthful and kind”</p> <p>“Being friendly and upbeat or sympathetic as needed”</p>
Institutional resources and care process (N=13, 4%)		
		<p>“Having tissues close by”</p> <p>“Teamwork between doctors”</p> <p>“Being on time”</p>
*codes counted once per patient		

