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Article in *Psycho-Oncology* · December 2018

DOI: 10.1002/pon.4963

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## PAPER

# Cancer survivors' experiences with breakdowns in patient-centered communication

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## Funding information

Houston VA Center for Innovations in Quality, Effectiveness, and Safety, Grant/Award Number: CIN 13-413; National Cancer Institute, Grant/Award Number: P20CA137219

## Abstract

**Objective:** This study analyzed cancer survivors' communication experiences that fell short of being patient-centered. Patients' descriptions of communication “breakdowns” were analyzed according to domain (eg, information exchange, fostering relationships, and managing emotions), whether it was a breakdown of commission (what was communicated) or omission (what should have been communicated) and whether it involved a clinician or the health care organization.

**Methods:** Cancer survivors (from an online panel of patients) completed the Patients Assessment of Communication Experience measure. Ratings less than “excellent” elicited a prompt asking where communication fell short. Communication breakdowns were categorized as one of commission/omission, if it involved a clinician/health care system, and within which communication domain. Thematic analysis explored how communication breakdowns affected respondents' cancer care experiences.

**Results:** Overall communication was rated as less than excellent by 153 respondents, of which 79 identified a specific communication breakdown. Over half ( $n = 43$ , 54%) were problems of omission, mostly attributed to interaction with health care organizations ( $n = 25$ ). Breakdowns of commission ( $n = 36$ , 46%) occurred primarily within clinical encounters ( $n = 32$ ). Most breakdowns were problems of information exchange (49%) or fostering relationships (27%). Three overarching themes emerged—emotional fallout from unmet information needs, inattention to patient perspective, and uncertainty about navigation and team communication.

**Conclusions:** Patient-centered communication breakdowns create distress that worsens patients' cancer care experiences. Communication skills training for clinicians should address listening, perspective taking, and assessing/satisfying patients' information and emotional needs. Health care organizations should enhance processes to provide timely, useful information to patients.

## KEYWORDS

cancer, communication breakdowns, information exchange, oncology, patient-centered communication, physician–patient relationships

## 1 | BACKGROUND

Effective communication among health care providers, patients, and families is critical for achieving patient-centered medical care.<sup>1</sup>

Productive interactions are not only important for achieving quality cancer care delivery, but they also contribute to improved outcomes for cancer patients.<sup>2,3</sup> Unfortunately, patient-centered communication in cancer care is often lacking. Surveys report that a sizeable

percentage of patients see their communication with cancer care providers as less than optimal,<sup>4-6</sup> especially with respect to compassion, receiving information that is timely and relevant, respecting patient preferences, and ensuring coordination of care.<sup>7</sup> Dissatisfaction with their interactions with health care providers can be considered communication “breakdowns” and in the minds of patients, can be as distressing as medical errors.<sup>8</sup> To date, there have been few in-depth analyses of breakdowns in patient-centered communication in terms of when, where, and why they occur during cancer care.<sup>9</sup>

This paper examines patient-cancer care provider (individual clinicians and the health care organization) communication breakdowns through the lens of NCI's functional model of patient-centered communication.<sup>7</sup> This conceptual framework is grounded in the notion that patient-centered communication consists of communication that brings the patient's perspective into the consultation, promotes understanding of the psychosocial context of the patient's health, involves patients in their care, and produces decisions that are based on the evidence, are consistent with patient values, and are feasible to implement. This model identifies six communication outcomes that are critical for achieving patient-centered cancer care—effectively exchanging information, fostering healing relationships, responding to emotions, making quality decisions, managing uncertainty, and enabling self-care. Effective communication within these domains affects cancer patients' perceptions of the quality of their cancer care<sup>10,11</sup> and are pathways to improved cancer care outcomes.<sup>12-16</sup>

Communication breakdowns can be analyzed in two respects. First, similar to research on medical errors,<sup>17,18</sup> communication problems may be ones of *commission* (eg, providing confusing information, showing disrespect, and disregard for the patient's concerns) or breakdowns of *omission* (eg, insufficient information, delays in response, and inadequate self-care resources). Second, patient-centered communication involves more than the communication patients have with a *particular clinician* (eg, a physician, nurse, or technician); it also is affected by how patients interact with the *health care organization* itself (eg, delays in test results and difficulty contacting the appropriate specialist).<sup>7,19,20</sup>

This investigation explored cancer survivors' communication experiences with their past cancer care, particularly with respect to where their communication with providers “fell short.” We examined three research questions. First, how are cancer survivors' accounts of breakdowns distributed across the key domains of patient-centered communication? Second, to what extent do accounts of communication breakdowns represent problems of commission or omission with either a particular clinician/staff member or with the cancer care organization as a whole? Third, what broader narrative themes are revealed in cancer survivors' accounts of how communication breakdowns affected the quality of their cancer care experiences?

## 2 | METHODS

### 2.1 | Research participants

Participants were members of an online panel of patients associated with a large health care system. Panel members are adults covered

by the system's health care plans and who have provided consent to be contacted about research participation. The panel also serves as a platform for structured feedback regarding patient experience. The study was reviewed by the Kaiser Permanente Colorado IRB and determined to be exempt given the panelists' prior consent.

### 2.2 | Procedure

A random sample of panelists received a survey invitation and initial screening survey. Those who reported ever having been diagnosed with cancer (regardless of where they received their cancer care) were eligible to continue. An incentive valued at \$10 was provided.

Participants completed an online version of the Patient Assessment of Communication Experience (PACE) measure,<sup>6</sup> a self-report questionnaire grounded in the NCI model of patient-centered communication.<sup>7</sup> The PACE includes seven distinct item sets assessing cancer survivors' experiences across the cancer continuum overall (from the time cancer was suspected until the present) and within specific phases (eg, diagnosis, treatment decision making, and receiving chemotherapy). This investigation focused on participants' overall communication experience, from the time cancer was suspected to the present (ie, the time of the survey). Respondents who provided a rating other than Excellent (ie, Very Good, Good, Fair, or Poor) were prompted to describe where their communication fell short. All responses were copied verbatim and added to a spreadsheet for analysis.

### 2.3 | Data analysis

The first phase of data analysis was a directed content analysis<sup>21</sup> in four steps. First, we determined whether the respondent's account qualified as a codable communication breakdown. Some comments (eg, “No problems with my care,” “Had to wait 6 months before I got a follow up appointment”) did not qualify as a specific communication breakdown and were excluded. Second, we determined whether the account included one or more communication breakdowns. For example, the comment, “The doctor didn't listen to our concerns at the follow up visit,” would be coded as one communication breakdown. If that same respondent added, “we also had delays in getting the clinic to return our phone calls,” that would be a second communication breakdown. The third step was to categorize each communication breakdown as (1) one of commission (something was communicated poorly or inappropriately) or omission (something was not communicated or not communicated in a timely fashion) and (2) whether it involved an individual clinician/staff member or the health care organization.

The final step in the content analysis was to categorize whether the complaint fell within one or more of the patient-centered communication domains from the NCI model (exchanging information, fostering relationships, managing uncertainty, responding to emotions, decision making, and enabling self-care). Whereas we used mutually exclusive coding when placing breakdowns into categories of commission/omission, and whether with an individual clinician or the

health care organization, it is possible a communication breakdown could involve more than one communication domain. For example, "we received too little information to understand our options (information exchange) and we needed that because we were scared (responding to emotions)." For the content analysis, two members of the research team (K.M. and R.S.) independently categorized each response. The coders then compared their respective categorizations and resolved any discrepancies.

The second phase of data analysis was a thematic analysis<sup>22</sup> to uncover broader themes about how communication breakdowns affected the respondents' cancer care experiences. For example, emotional distress may be a recurring consequence associated with problems across several communication domains (eg, information exchange, decision making, and responding to emotions) and could occur either within specific clinical encounters or with the health care organization. Two members of the research team (E.S. and R.S.) independently reviewed respondents' accounts to identify cross-cutting themes. After initial coding, both coders compared their list of themes, identified areas of similarity, reconciled differences, and reached consensus on overarching themes that were represented across the respondents' accounts.

### 3 | RESULTS

#### 3.1 | Participant characteristics

Of 366 respondents in the survey, 153 (42%) rated the quality of their overall communication experiences as less than excellent. Similar to the overall sample, the subsample of 153 were mostly White, highly educated, and majority women (Table 1). This subsample of respondents did not differ from the subsample reporting excellent communication with respect to sex, race/ethnicity, type of cancer, and time since diagnosis. However, those reporting less than excellent communication tended to be younger ( $t = 2.45, P < 0.02$ ).

#### 3.2 | Sample of communication breakdowns

Of respondents reporting less than excellent overall quality of communication, 87 answered the question asking where their communication fell short. Of these, 26 responses did not address a specific communication breakdown (eg, "communication was poor," "overall, my care was good," "had to wait too long for an appointment") leaving 61 as the total number of respondents providing a codable response. The 61 respondents whose responses met inclusion criteria did not differ from the other 92 on demographics, type of cancer, and time since diagnosis although there was a trend for proportionally more participants with a high school education to be in the nonresponse and noncodeable response group ( $\chi^2 = 6.67, P = 0.083$ ). Of the 61 meeting inclusion criteria, 12 participants provided accounts that involved more than one communication breakdown. Each breakdown was treated as a separate communicative event creating a total of 79 breakdowns to categorize as ones of commission/omission and whether it involved a clinician or the health care organization. Of the 79 communication breakdowns, 13 were coded as involving two

**TABLE 1** Characteristics of the sample

Demographic and health-related characteristics*	Sample responding less than "excellent" to overall communication quality (n = 153)
<b>Race/ethnicity</b>	
White	124 (81.0%)
Black	11 (7.2%)
Asian	2 (1.3%)
Other/missing	16 (10.5%)
<b>Gender</b>	
Female	89 (58.2%)
Male	64 (41.8%)
<b>Education</b>	
High school or less	9 (5.9%)
2-year degree/some college	51 (33.3%)
4-year college graduate	26 (17.0%)
More than 4-year college/post graduate	67 (43.8%)
<b>Marital status</b>	
Married	92 (60.1%)
Living with partner	10 (6.5%)
Single/separated	21 (13.7%)
Divorced	23 (15%)
Widowed	7 (4.6%)
Age (years)	M = 60.9 (SD = 10.2)
<b>Type of cancer</b>	
Breast	33 (21.6%)
Prostate	17 (11.1%)
Colorectal	7 (4.6%)
Lung	2 (1.3%)
Cervical	3 (2.0%)
Skin	52 (34.0%)
Other nonskin	33 (21.6%)
Multiple cancers	6 (3.9%)
<b>Time since diagnosis</b>	
Less than 3 months	4 (2.6%)
3-6 months	4 (2.6%)
7-11 months	4 (2.6%)
1-2 years	18 (11.8%)
More than 2 years	122 (80.3%)

patient-centered communication domains (eg, information exchange and decision making and information exchange and responding to emotions). Table S1 (supporting information) provides examples of respondents' comments according to type of communication breakdown and which communication domain(s) was involved.

#### 3.3 | Distribution of breakdowns

As shown in Table 2, just over half (54%) of the communication breakdowns were problems of omission (something was not communicated that should have been). Almost two thirds of the breakdowns (63%)

occurred with an individual clinician/staff member. The largest percentage (41%) of responses within cells were communication breakdowns of commission during a particular encounter followed by problems of omission (32%) when dealing with the health care organization. A number of communication breakdowns (23%) also were attributed to omission within a clinical encounter.

With respect to communication domain, over half (52%) of the breakdowns were problems with information exchange. In descending order of frequency, the remaining breakdowns were problems related to fostering healing relationships (28%), helping with emotions (11%), and decision making (5%). Although no responses fell within the managing uncertainty and enabling self-care domains, a category labeled "communication problems with the clinical team" was created to categorize three of the responses.

### 3.4 | Overarching themes capturing patient experience

Taken collectively, cancer survivors' comments tapped into three broad themes revealing how communication breakdowns contributed to poorer experiences when receiving cancer care. The first is labeled *Emotional fallout from not satisfying information needs*. Problems with information exchange were frequently issues of inadequate information with respect to amount and/or timeliness. Interestingly, these were often attributed to problems when dealing with the health care organization. These events had direct emotional consequences such as anxiety and distress as noted by several respondents.

*Test results were not available when promised and no one let me know--so I worried needlessly that things were worse. I did not understand the process and I was left in the dark initially about how things were to proceed.*

*There were necessarily time-lags, with no information available, which were nerve-wracking.*

*I was diagnosed during my very first Mammogram! .....I was put in a room by myself for a really long time and no one bothered to give me any updates or tell me what was going on .... I was left there to wait all by myself and worry my head off!*

Breakdowns in information exchange when interacting with individual clinicians also added stress to making treatment decisions. These breakdowns spanned a variety of information exchange problems, including overload;

*The (radiologist) bedside manner increased my fear almost a hundred fold. He gave me information in a way and setting that almost scared the life out of me. Also I was given so much information that it was really hard to decide which choices to make.*

lack of guidance processing the information;

*Regarding my choices as to whether to have a lumpectomy or breast removal, I'd like the doctors to be more involved. How could I make that decision? I know nothing and I was frightened.*

and the perception of biased information.

*My doctor put down all other methods of treatment as not effective, "surgery is the gold standard," and as such the only way to treat my cancer.*

The second theme, *Inattention to the patient's perspective exacerbates distress*, represented communication breakdowns of commission regarding what clinicians were doing, perhaps unintentionally, that worsened patients' cancer care experiences. For example, one patient recounted:

*My Oncologist, made me and my husband feel terrible when we had our first consult. She had a lot of exposed cleavage with a very short skirt which was very hard for me and my husband since I had just had a bilateral mastectomy and we were both mourning the loss of my breasts.*

Patients also described insensitive, inappropriate, and unprofessional statements made within earshot.

*I had been extremely ill prior to the surgery. The surgeon made the comment (to a nurse) that if I was going to die anyway, why do the surgery? I think it was not professional to make that comment in front of me.*

*One of the ER personnel who was the first to see me mentioned "hospice care" before I had even seen the Oncologists or admitted to the hospital. I knew that I was very sick at that time, but I remember vividly through the haze of uncertainty that was NOT appropriate.*

In other instances, comments perceived as dismissive were interpreted as a lack of empathy with what the patient was experiencing.

*The initial appointment with the Oncologist was difficult due to resistance from her nurse. Her comment was 'Let*

**TABLE 2** Distribution of different types of communication breakdowns

Communication breakdowns (N = 79)	Acts of commission N (%)	Acts of omission N (%)	Total N (%)
With a clinician/staff members	32 (41)	18 (23)	50 (63)
With the health care organization	4 (5)	25 (32)	29 (37)
Total	36 (46)	43 (54)	79

*me make sure that I have got this before I change a ..... meeting on the Doctor's schedule, you want me to make an appointment for a non-invasive tumor? My tumor was in-situ, (the size of a lime against my chest wall) and my response was "Yes because it's very invasive to me.*

*There were only a couple of times I went to the emergency room, or ended up admitted to the hospital that a doctor or nurse did not listen or allow me to communicate my feelings or concerns.*

The final recurring theme was labeled *Uncertainty about the workings of the health care organization*. These breakdowns address problems of navigation and team communication that created uncertainty about who to see, what to communicate to whom, and/or who was communicating with whom.

*when I had a question and was at the surgeon, he told me I would need to ask the oncologist - while I understand that not all DRs have all the information it was difficult to know who to address my concerns.*

*I did have many helpful caregivers at (the) clinic, but I never felt that my care was coordinated. I was left to do it myself.*

Finally, some respondents believed there were communication breakdowns within the clinical team.

*I saw a lot of different people and I was never sure if there was a lot of communication between them and I felt passed around a little bit. I had to ask a lot of questions and (do) a lot of research on the internet.*

*(problem was) whether the clinical team were communicating with one another or reporting. I sometimes felt that I was transmitting to the surgeon information that the dermatologist should have provided.*

## 4 | DISCUSSION

Poor communication contributes to unnecessary distress for cancer patients, in addition to worsened clinical and psychosocial outcomes.<sup>3,23</sup> This study analyzed cancer survivors' experiences when their communication with providers fell short of expectations. Treating these accounts as communication breakdowns, we analyzed what domain of patient-centered communication was involved (eg, information exchange, responding to emotions), whether the breakdown was one of commission or omission and whether it involved a clinician or the health care organization. We also extracted overarching themes of how breakdowns impacted the respondents' cancer care experiences. The findings have important implications for research and clinical practice.

First, consistent with previous research,<sup>8,24,25</sup> accounts of communication breakdowns often arose from ineffective information

exchange (eg, insufficient, not timely, biased, and overload) and poor clinician–patient relationships (eg, insensitivity, not listened to, and lack of compassion; see Table S1, supporting information). Communication breakdowns involving more than one communication domain almost always involved information exchange. For example, some breakdowns in information exchange also reflected poorly on the clinician–patient relationship (lack of attention to the patient's needs), responsiveness to the patient's emotions (anxiety and worry), or decision making (too little, too much, or confusing information).

Communication breakdowns contributing to poorer clinician–patient relationships reflected problems reported in previous research—the communication lacked compassion,<sup>26</sup> lacked commitment,<sup>27</sup> was insensitive to the patient's feelings,<sup>28</sup> did not make the patient feel “known,”<sup>23,29</sup> or showed little respect for the patient's opinion.<sup>30</sup> These accounts highlight patients' priorities for timely, understandable, and meaningful information throughout the course of cancer care within a health care system that supports caring, compassionate clinician–patient relationships.<sup>31,32</sup>

Second, the majority of communication breakdowns (54%) were ones of omission—not what clinicians or health care organizations did but what they did not do. Communication breakdowns of omission most often were attributed to the health care organization. These focused primarily on information exchange such as the need for more and timely information (eg, delays in getting test results back and returning phone calls) and confusion navigating and working with the health care system (eg, where to go for follow up tests, and why one doctor did not have information that was provided to another doctor).

Third, while communication breakdowns attributed to the health care organization typically involved insufficient or delayed information, breakdowns of commission were primarily associated with individual clinicians/staff members and spanned several communication domains, including information exchange, building healing relationships, responding to emotions, and making decisions. Communication breakdowns with individual clinicians were problems of which clinicians were likely unaware. For example, the accounts in Table S1 (supporting information) and the thematic analysis revealed that some clinicians may not have known how the patient might interpret their behavior (eg, the breast cancer patient's reaction to her physician's display of “cleavage” and dismissing an ovarian cancer patient's concern about postmenopausal bleeding as “normal”) or carelessness (ER doctor mentioning hospice care before the patient saw her oncologist). In these cases, patient-centered communication skills are more than simple behavioral prescriptions (eg, use everyday language and show empathy); they also require a mindset, such as situational awareness<sup>33</sup> and perspective-taking<sup>34</sup> that can guide clinicians toward situationally appropriate and helpful responses.

Finally, the most common thread in the thematic analysis was that breakdowns in patient-centered communication have psychological consequences for cancer patients, emotional distress in particular. Some respondents expressed anxiety and worry when needed information was delayed, confusing, or inadequate. There were also negative emotions associated with feeling dismissed, disrespected, or not taken seriously. Respondents experienced frustration or uncertainty about not knowing who to turn to for questions, where to go next



in their cancer care, and wondering whether their doctors were sharing information about their care.

## 5 | STUDY LIMITATIONS

The study has several limitations, including a relatively small sample of respondents who were mostly White, female, and highly educated. In addition, there was variability regarding when respondents had their cancer treatments. Treatment for some respondents ended “years ago” whereas for others treatment ended within the past few months. Different degrees of retrospective sense making may be reflected in the responses. Finally, we did not drill down into problems within specific phases of cancer care; rather, the breakdowns reported in this study were situated across the entire cancer continuum from diagnosis to post treatment transitions to primary care.

## 6 | CLINICAL IMPLICATIONS

Although the majority of patients in our survey rated their communication as “Excellent,” 42% reported less than optimal communication experiences. Their accounts of communication breakdowns point to specific types of skills clinicians need to master such as listening, being respectful, perspective taking, offering emotional support, and giving clear, useful information.<sup>33,34</sup> Importantly, communication breakdowns are “contextualized” by such factors as the patient's needs, type of cancer, clinic workflow, and clinician action/inaction (eg, giving too much or too little information). The complexity of these experiences argues against a “one size fits all” approach to communication training. Pedagogical activities focused on mindful practice, problem-based learning, and feedback could help prepare clinicians for effectively addressing the patient's unique communication needs.<sup>35,36</sup>

Second, patients also report communication breakdowns when engaging the health care organization. Health care organizations could gather valuable information by asking patients if any communication “fell short.” As these findings demonstrate, many patients are willing to provide feedback about their communications experiences and the emotional consequences. Using principles of the Chronic Care Model,<sup>32</sup> health care organizations could use these reports to design system-level efforts to improve communication on a number of fronts, such as helping patients navigate between different doctors, improve communication among different clinicians, and reduce time lags between tests and reporting diagnosis.

## 7 | CONCLUSION

Patient-centered communication breakdowns create distress and worsen cancer patients' experiences. Such breakdowns include acts of commission where something was communicated poorly (confusing) or inappropriately (feeling disrespected) or problems of omission (insufficient or delayed information). Patients may experience breakdowns when interacting with individual clinicians or staff as well as when interacting with the health care organization. Breakdowns occurred within several domains of patient-centered communication;

however, information exchange and fostering healing relationship were the domains within which these respondents were most likely to report problems.

## ACKNOWLEDGEMENTS

Data collection for this study was funded by the National Cancer Institute (P20CA137219). Dr Street is supported by the Houston VA Center for Innovations in Quality, Effectiveness, and Safety (CIN 13-413).

## CONFLICT OF INTEREST

The authors report no conflicts of interest.

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#### SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**How to cite this article:** Street Jr RL, Spears E, Madrid S, Mazor KM. Cancer survivors' experiences with breakdowns in patient-centered communication. *Psycho-Oncology*. 2019;28:423-429. <https://doi.org/10.1002/pon.4963>