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Patients' Perspective on Communication: Elderly Cancer Survivors' Experiences with their Doctors

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ABSTRACT

This study focused on perspectives of 176 older adults who reported a cancer diagnosis. Respondents were interviewed regarding positive and problematic communication experiences with their physicians, offering an "insider perspective" on their lived experiences. Using a qualitative approach, we classified six themes reflected in patient narratives. About one-fifth of the respondents (19%) offered examples of problematic health care and communication experiences, while two-thirds (65%) provided examples of positive experiences with their physicians. This data offers evidence about the salience of the positive doctor-patient communication experiences for the elderly. Although examples of problematic communications were less frequent, they are notable in calling attention to areas for needed improvement in physician communication with their patients. In particular, many patients reported experiencing discordance with their doctors. An important finding was a differentiation of two types of discordance; the disagreement either occurred exclusively between the doctor and the patient, or it commenced between multiple doctors and was consequently translated to the patient. The themes garnered from this study suggested areas of positive and problematic communication that may become directed towards patient proactivity or physician education.

INTRODUCTION

Cancer is a life threatening illness that poses many challenges to survivors. However, by offering patients information, social support, empathy, at-

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tentive listening, and collaborative care, physicians can provide positive communication that may serve important functions in improving patients' experiences (Arora, 2003; Epstein & Street, 2007; Ha, Anat, & Longnecker, 2010). Physicians must pay particular attention to initiating positive communication with older patients because older patients may lack assertiveness and tend to be compliant (Kahana, et al., 2009). Furthermore, elderly patients are more prone to having their cancer being treated inadequately (Fentiman, Tirelli, & Monfardini, 1990). Due to a growing number of cancer incidences with a particularly higher incidence occurring in the elderly, it is important to direct doctor-patient communication research towards the population of the aging patients diagnosed with cancer (Devesa, Blot, Stone, Miller, Tarone, & Fraumeni, 1995). Reflections by these elders about their communication experiences may offer useful insights toward improving doctor-patient communications for diverse age groups and illnesses.

The present study is unique in considering reports given by older cancer patients evaluating their health care and their communication with their doctors. In the expanding body of literature attempting to analyze the quality of doctor-patient communication, there has been relatively little patient-driven data, particularly based on elderly patients (Kahana E. & Kahana, 2007). Reviews of the literature on doctor-patient communication reveal that few studies regarding helpful communications in cancer treatment focus on patients' perspectives (Stajduhar, Thorne, McGuiness, & Kim-Sing, 2010). In fact, many studies are done from the researchers' perspective (Roter & Hall, 2006), where a third party rates the quality of communications reflected by voice or video recordings of doctor-patient communication in controlled settings.

By collecting responses directly from the patient, we were able to obtain both qualitative and quantitative information. This differs from the observational approach, where only quantitative data can be acquired (Arora, 2003). Our research appreciates the value of both the quantitative and qualitative research method regarding studies in communication. We thus used a mixed methods design that can combine benefits of considering responses to both closed- and open-ended questions. Combining quantitative information with complementary qualitative responses enhances and adds more depth to the analysis. Because "human communication is an ongoing dynamic process and not a one-way, fixed sequence of events" (Hagihara & Tarumi, 2006), it is beneficial to allow the respondent to freely elaborate on open-ended questions without constraints or limits. This allows us to capture a broader spectrum of the patients' perspectives and "understand the world as seen by the respondents" (Patton, 2002). In turn, such understanding can offer guidelines for making improvements in patient care and achieving greater patient satisfaction (Tarintino, 2004).

METHODS

Sample:

Interviews were conducted with 176 elderly adults who had reported cancer diagnosis from participants of a panel study of 1,107 community-dwelling elderly adults. The respondents ranged in age from 65 to 102 years, with a mean age of 80 years (SD=7.5). 65% were female and 55% were married. 95% classified themselves as white, 4% as black, and 1% as other. The most common cancer diagnosis was breast cancer at 24%, followed by prostate cancer and melanoma at 15% and 13%, respectively. The remainder of the respondents had less common forms of cancer, which included colorectal, bladder, and lung cancer. Time since cancer diagnosis ranged from less than one to 65 years, with a mean of 10.3 years (SD=11.9). 36% of the respondents had at least one previous cancer experience.

Procedures:

In personal interviews, both closed- and open-ended questions were utilized to capture the elderly respondents' health care and communication experiences, emotions, and opinions regarding their doctors. For the closed-ended questions, the interviewers recorded whether the respondents experienced positive and/ or problematic communication, along with the extent of such communication. As for the open-ended questions, responses were coded using a standardized staged content analysis process, where raters independently read narratives and coded them into categories (Patton, 2002). Respondent narratives of positive and problematic communication with doctors were analyzed to identify themes from the open-ended questions.

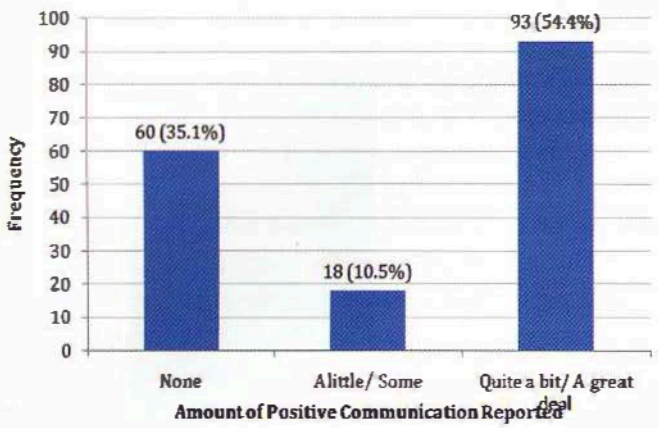

Figure 1. A U-shaped distribution describes the amount of positive communication received by respondents (N=171).

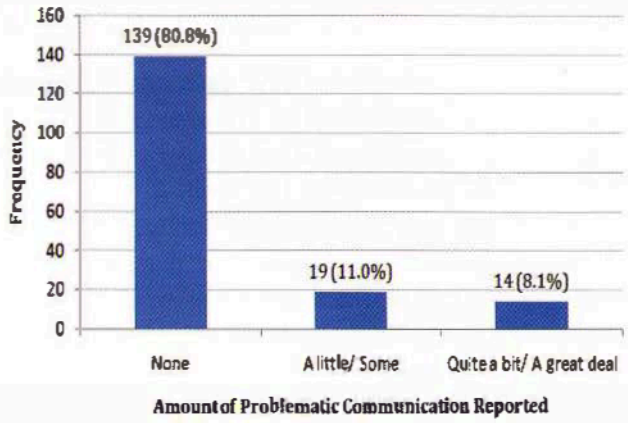

Figure 2. About one-fifth of the respondents experienced at least a little or some amount problematic conununication (N=172).

RESULTS

Responses to closed-ended questions regarding the amount of positive and problematic communication received from physicians are shown in Figures 1 and 2, respectively. Our data indicate that 64.9% of the sample experienced positive communication, while 19.1% reported problematic communication. Conversely, 35.1% of the respondents reported no positive communication experiences, while 80.8% reported no problematic communication. The two percentages within each comparison roughly complement each other; the difference between them may be accounted by the fact that reports of positive and problematic communication are not mutually exclusive.

A U-shaped pattern describes the distribution of the amount of positive communication reported. Most respondents (89.5%) reported either a large amount or no positive communication; few (10.5%) were in between. Over one-third (35.1%) of the respondents stated they did not receive any positive communication. As for problematic communication, a majority of the respondents reported no problems in communicating with their doctors (80.8%). The number of respondents who reported a little/ some problematic communication was roughly equal to the number of respondents who reported quite a bit/ a great deal of problematic communication (11.0% and 8.1%, respectively).

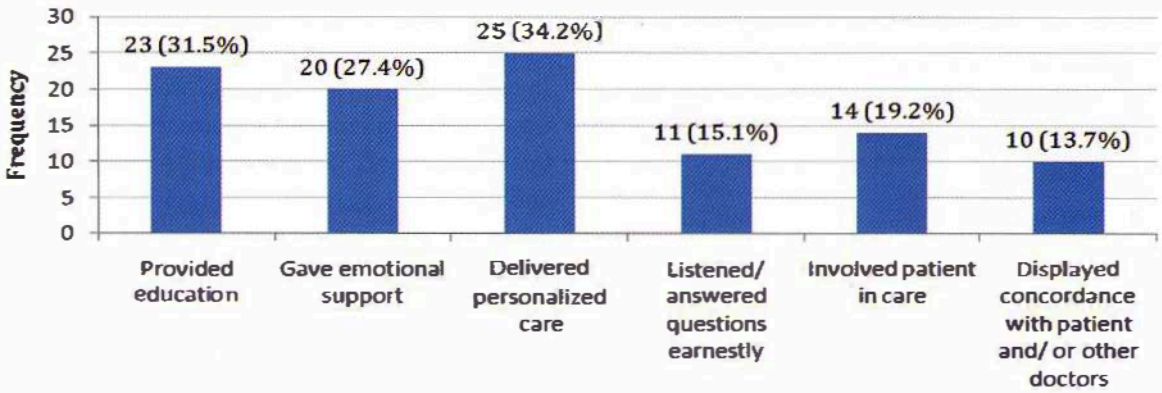

Figure 3. Six themes were drawn from respondents' examples of positive communication experiences (N=73). Some examples given by respondents may offer more than one theme, as they are not mutually exclusive.

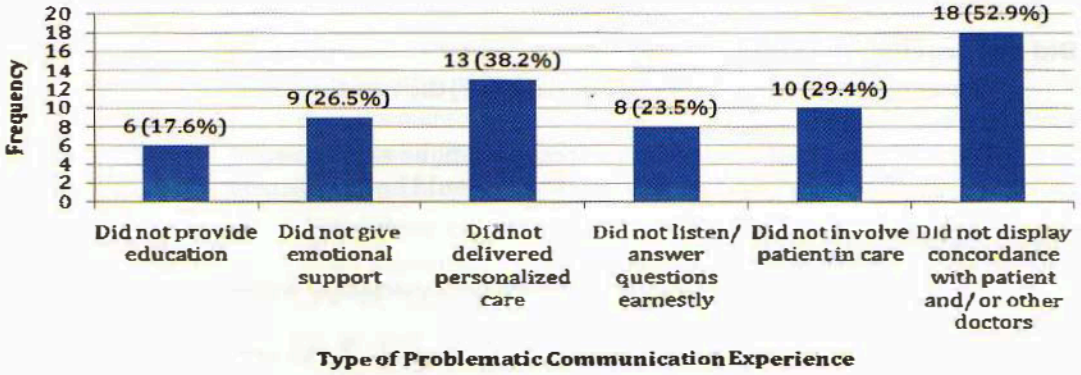

Figure 4. Themes drawn from respondents' examples of problematic communication experiences (N=34) reflected the absence of the positive communication themes. Some examples given by respondents may offer more than one theme, as they are not mutually exclusive.

Complementing the closed-ended responses, open-ended responses provided qualitative data that specified the types of communication respondents experienced. The following six themes, depicted in Figures 3 and 4, were identified in open-ended questions regarding positive experiences reported by patients: the doctor (1) provided education, (2) gave emotional support, (3) delivered personal care, (4) listened and answered questions earnestly, (5) involved the patient in care, and (6) concurred with the patient and/ or other doctors. For example, a patient who described her urologist as "very nice and kind" specifically noted how "he explained everything" and how she "trusted his opinion". This patient experienced communication that allowed her to receive education and personalized care from her doctor.

When referring to positive communication experiences, the 73 respondents commented most on how doctors delivered personalized care (34.2%), provided education (31.5%), and gave emotional support (27.4%). The following quote from a patient exemplifies a response categorized under the themes of personalized care and emotional support: "[My primary doctor] listened to me and [gave] me support. He knew I was upset because I had cancer again." Additional examples are provided in Table 1. Respondents also reported the following types of positive communication experiences: doctors listened/ answered questions

	*n (%)
Provided education	**23 (31.5%)**
- The urologist "gave me literature" and "provided statistical data as reference."	
- The doctor "explained my options thoroughly but left the final decision up to me."	
Gave emotional support	**20 (27.4%)**
- The surgeon "dropped everything to help me ... and talked me through all 10 months of chemo."	
- The doctors "were supportive and kind to me."	
Delivered personalized care	**25 (34.2%)**
- The surgeon "visited [me] in-person when I was in the hospital" and "called everyday to give a report when I was at home."	
- The doctors "were readily available by phone and answered any and all questions, no matter how trivial or unrelated."	
Listened/ Answered questions earnestly	**11 (15.1%)**
- The doctors "were readily available by phone and answered any and all questions, no matter how trivial or unrelated."	
- The urologist "listened to my concerns and supported me."	
Involved patient in care	**14 (19.2%)**
- The doctor "explained my options thoroughly but left the final decision up to me."	
- The surgeon "gave me choices and information so I could make the best decision for [myself]."	
Displayed concordance with patients and/ or other doctors	**10 (13.7%)**
- "One doctor told the other doctor I could take tamoxifin and [the second doctor] agreed."	
- The urologist's "attitude was the same as mine."	

Table 1. In many of the patients' positive communication examples, doctors delivered personalized care, provided education, and gave emotional support (N=73). Some examples given by respondents may offer more than one type, as they are not mutually exclusive.

	n (%)
Did not provide education	**6 (17.6%)**
- "I was not told anything about hot flash [or] the emotional trauma I experienced	
- The urologist "was completelyunresponsive; he said Ineeded my prostate removed anddidn't tellme I would be incontinent and impotent."	
Did not provide emotional support	**9 (26.5%)**
- "The urologist was cold; [he] performedthe cystoscopy without anesthesia. He was a sadist!"	
- "I had to wait six weeks from diagnosis to surgery; it was very worrisome."	
Did not deliver personalized care	**13 (38.2%)**
- "I have bad veins and [the doctors] wouldn't listen to me when I told them how to take my blood."	
- "The oncologist seemed aloof [and] uninterested."	
Did not listened/ answer questions earnestly	**8 (23.5%)**
- The OB/GYN was "abrupt and quick to answer."	
- "I have bad veins and [the doctors] wouldn't listen to me when I told them how to take my blood."	
Did not involve patient in care	**10 (29.4%)**
- "I didn't have the opportunity to ask questions."	
- "[The doctors] wanted to do more to me than I wanted."	
Displayed discordance with patients and/ or other doctors	**18 (52.9%)**
- The oncologist "said it was lymphoma; I have it in writing, but I'm not convinced."	
- "One doctor said I had cancer, one said I didn't, and one did not know."	

Table 2. Over half of the respondents who gave examples of problematic communication experienced discordance with their doctors (N=34). Additionally, many of the problematic communication experienced reflected a lack of personalized care. Some examples given by respondents may offer more than one type, as they are not mutually exclusive.

earnestly, involved patient in care, and displayed concordance with patients and/ or other doctors.

Problematic experiences that were reported reflected the absence of the above-mentioned themes bit regarding doctors' behaviors. As an example of a problematic experience, one patient interacted with a doctor who "wouldn't answer questions...wouldn't tell [her] what was going on, and didn't realize it was worse [to not tell her]." In this case, the patient did not receive sufficient education. Table 2 lists further examples of problematic communication.

When referring to problematic communication experiences, respondents commented most on doctors' discordance or lack of agreement regarding diagnosis or treatment. Half (52.9%) of the 34 respondents who provided such communication experiences reported doctor-patient discordance. Two types of discordance were observed; indirect and direct discordance. Indirect discordance was defined as disagreements rooted amongst doctors, which led to the patients' disbelief of the diagnosis or lack of confidence in the treatment. In the end, we observed that the patient's evaluation of health-related information differed from the doctor, which is the standard definition of discordance (Szasz & Hollender. 1956). 66.7% of the discordance cases fell under the indirect category. One such

case occurred when a patient consulted three opinions, only to find that "one doctor said [he] had cancer, one said [he] didn't, and one said he didn't know." The other type of discordance, which was defined as a disagreement isolated in the relationship between only the doctor and patient, accounted for 33.3% of the discordance cases. Since there was no third party involved, we labeled these cases as "direct discordance." An example of direct discordance comes from the following patient quote: "We told [the doctor] twice the spot was changing, but he said it was okay. We insisted on biopsy and [the results showed] it was melanoma."

Another category that garnered a higher number of responses was a lack of personalized care; 38.2% of the responses mentioned this type of negative communication. An example of this theme occurred when a "doctor did not realize a side effect was coming on," since each person responds to treatments and medications in a unique way. Furthermore, 29.4% of respondents reported their doctor did not involve them in their care. For example, one respondent experienced "some problems reaching the doctor," while another felt his surgeon was "non-communicative." "My wound kept draining, so I had to go back for a second surgery to stop the drainage," he said. A further lack of patient involvement is evidenced by the fact that this patient was never told instructed to go to an oncologist.

DISCUSSION

Overall, older cancer patients appreciate positive communications from their physicians; particularly in education, emotional support, and personalized care. These three categories are linked through their direct effect of involving the patient in care. Because education improves patient understanding of medicine (McBean & Blackburn, 1982), patients who receive appropriate education have a factual foundation towards the decision of their treatment. Those who receive emotional support and personalized care are more compelled to voice their concerns to their doctors (Maguire, Faulkner, Booth, Elliott, & Hillier, 1996). By being more open, they will be able to receive better care from their doctors, since doctors report that "openness" is a trait of helpful patients (Steinmetz & Tabenkin, 2001). These findings support the notion that the patient can be more proactive in achieving a positive experience in interacting with their doctor (Kahana E. & Kahana, 2003; Kahana E. & Kahana, 2007; Kahana E., Kahana, Wykle, & Kulle, 2009).

In considering the preponderance of positive communications reported by older patients, we must recognize that older adults may under-report problematic communication due to the social desirability of expressing satisfaction with their care (Fabroni & Cooper, 1989; Ray, 1988). Because of the basic human tendency to present oneself in the best possible light, respondents are often unwilling to accurately report on sensitive topics (Fisher, 1993). Additionally, given the long-term survivorship of many respondents, we must also consider potential recall bias, where longer periods of recall correlate with increased inaccuracy of respondents' reports (Clarke, Fiebig, & Gerdtham, 2008). Therefore, the frequency of problematic communication occurrences may be higher than reported in this study and respondents may have described examples of problematic communication with less breadth and detail.

In addition to positive communication examples, problematic communication examples also contribute to the concept of patient proactivity. Many of the respondents who experienced problematic communication with their doctors noted a satisfactory change after they took initiative and switched doctors. For example, instead of giving an example of a problematic experience, one patient gave the following response: "Once I changed my primary care doctor, everything was fine."

This research also provides clinical implications for the doctor as well as the patient in terms of creating a more positive health care experience. These findings, particularly the positive communication themes regarding patient-desired interactions drawn from patients' responses, reflect the skills needed by doctors to diminish the impersonality of modern medical science (Dixon, Sweeney & Pereira Gray, 1999). In an era where concrete evidence like lab results and other quantitative data dictate diagnosis, many doctors may not fully appreciate the importance of using positive communication to relay the diagnosis of a disease to their patients.

In addition to analyzing positive narratives, by considering open-ended responses from patients who had problematic experiences, we can suggest steps that physicians can take towards improved communication with their patients. Giv-

en the large proportion of respondents who reported a lack of positive communication, doctors must understand patients' perceptions of problematic communication experiences because it highlights areas in which doctors can focus more attention. For example, since over half of the problematic communication examples fell under the category of discordance, doctors should direct more attention toward enhancing concordance.

In our study, respondents reported two types of discordance; direct and indirect. Direct communication challenges the essence of the doctor-patient relationship, as the patient is directly involved in the disagreement. In this case, the patient takes on one belief, while the doctor takes on another. This straightforward type of discordance raises questions that act as a cause for conflict. In the end, we observe a relationship lag, where the two parties are unable to meet at the same level. On the other hand, in indirect communication, the patient is more removed from the conflict. The patient feels the secondhand effects of the problematic doctor-doctor relationship, where the doctors disagree with each other. These effects, which are ultimately the origin of indirect communication, are observed when doctors do not clearly communicate their differing opinions to the patient. Consequently, indirect discordance implies ambiguity and a cause for confusion. This raises questions of direction for treatment and thus, the patient-doctor relationship suffers from not a relationship lag, but an information lag.

By examining the possible causes of both types of discordance, we can provide ways to prevent this common theme in problematic communication. For example, when patients disagree with their doctors in direct discordance, the disagreement is associated with psychological stress and thus decreases the ability of the patient to process information (Sewitch, Abrahamowicz, Dobkin, & Tamblyn, 2002). To relieve psychological stress in the elderly population, one must factor in not only the context of the stress, but the variability on how each elderly patient responds to a stress (Lazarus & DeLongis, 1983). Thus, to prevent direct discordance, physicians must use at least three of the positive communication themes obtained from this study: they must listen and answer questions earnestly to clear any confusion due to the psychological stress, they must provide emotional support to alleviate the mental and physical hardships created by cancer diagnosis and treatment, and they must deliver personalized care to account for the variation in stress coping of the elderly.

On the other hand, in the case of indirect discordance, problematic communication occurs from a lack of clarity when the doctor passes information to the patient. By providing patients with records substantiating their assessment of the patient's situation and available options (i.e. copies of test results or data from prior research), doctors are able to avoid cases of indirect discordance; this points to the value of providing patient education. Additionally, because patients are likely to have questions regarding doctors' differing opinions, doctors must be keen on listening and answering questions earnestly.

Our research provided valuable insights into the world of communication between doctors and elderly patients diagnosed with cancer. Examples of both positive and problematic communications noted by patients suggest avenues for improving communication in healthcare for both patients and doctors.

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