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Assessing patients' experiences with communication across the cancer care continuum☆

Kathleen M. Mazor[a,*], Richard L. Street Jr.[b], Valerie M. Sue[c], Andrew E. Williams[d], Borsika A. Rabin[e], Neeraj K. Arora[f]

[a] Meyers Primary Care Institute, 630 Plantation Street, Worcester, MA 01605, USA
[b] Department of Communication, Texas A&M University, 456 Ross Street, College Station, TX 77843, USA
[c] Kaiser Permanente, 300 Lakeside Drive, Oakland, CA 94612, USA
[d] Maine Medical Center Research Institute, 81 Research Drive, Scarborough, ME 04074, USA
[e] Department of Family Medicine, University of Colorado-Denver, 13001 E 17th Place, Aurora, CO 80045, USA
[f] Patient-Centered Research Outcomes (PCORI) Research Branch, 1828 L Street NW #900, Washington, DC 20036, USA

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ABSTRACT

Objective: To evaluate the relevance, performance and potential usefulness of the Patient Assessment of cancer Communication Experiences (PACE) items.
Methods: Items focusing on specific communication goals related to exchanging information, fostering healing relationships, responding to emotions, making decisions, enabling self-management, and managing uncertainty were tested via a retrospective, cross-sectional survey of adults who had been diagnosed with cancer. Analyses examined response frequencies, inter-item correlations, and coefficient alpha.
Results: A total of 366 adults were included in the analyses. Relatively few selected *Does Not Apply*, suggesting that items tap relevant communication experiences. Ratings of whether specific communication goals were achieved were strongly correlated with overall ratings of communication, suggesting item content reflects important aspects of communication. Coefficient alpha was ≥.90 for each item set, indicating excellent reliability. Variations in the percentage of respondents selecting the most positive response across items suggest results can identify strengths and weaknesses.
Conclusion: The PACE items tap relevant, important aspects of communication during cancer care, and may be useful to cancer care teams desiring detailed feedback.
Practice implications: The PACE is a new tool for eliciting patients' perspectives on communication during cancer care. It is freely available online for practitioners, researchers and others.

1. Introduction

"The most important goal of a high-quality cancer care delivery system is meeting the needs of patients and their families" [1].

Patient-centered communication (PCC) is key to meeting patients' and families' needs, and is a fundamental requirement for high quality cancer care [1]. There is a substantial and convincing body of evidence that PCC contributes to better patient outcomes [2]. However, there is also considerable evidence that PCC is not occurring consistently [3]; that poor communication is distressing to patients and damaging to the clinician-patient relationship [4], and that communication problems can contribute to physical harm and poor medical outcomes [5,6].

The first step in improving communication during cancer care is to gather information on the current state of practice, including what is being done well, and where current practice is falling short [7–9]. Both types of information can help to drive care improvements, especially when they specify important, achievable outcomes to target. Once interventions and resources are directed to

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* Corresponding author.
E-mail addresses: Kathy.Mazor@meyersprimary.org (K.M. Mazor), r-street@tamu.edu (R.L. Street Jr.), valerie.m.sue@kp.org (V.M. Sue), aewilliams@mmc.org (A.E. Williams), borsika.a.rabin@gmail.com (B.A. Rabin), narora@pcori.org (N.K. Arora).

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improving communication, assessments are needed to evaluate intervention effectiveness.

Interviews with patients, family members, clinicians and health care organization leaders document that stakeholders would value a communication monitoring system that would systematically assess patients' communication experiences over time, across different phases of cancer care [10]. The recent explication of a six function model of PCC in cancer care by Epstein and Street provides a strong a conceptual framework for developing communication measures as a foundation for such monitoring systems [2].

Here we describe initial testing of a new communication measure, the Patient Assessment of cancer Communication Experiences (PACE), intended to assess the patient's perspective on communication over the course of cancer care. We evaluate the relevance, performance and potential usefulness of the PACE items, using responses collected via a retrospective, cross-sectional survey of adults who had been diagnosed with cancer. We also provide an illustrative example of how implementing these items could result in important feedback for care teams.

2. Methods

2.1. Item development

We developed multiple sets of items to assess achievement of key communication goals across each phase of cancer care from the first suspicion of cancer through the conclusion of treatment. We did not develop items focused specifically on palliative care, hospice or end of life issues. Items were written to assess each of the six functions of the Epstein-Street PCC framework (fostering healing relationships, exchanging information, responding to emotions, making decisions, managing uncertainty, and enabling patient self-management) [2]. Items focused on the patient's perception of whether specific communication goals had been achieved, rather than whether particular communication behaviors had occurred. For example, an item such as "The doctor discussed the risks and benefits of my treatment options" focuses on behavior, rather than the goal of that behavior, patient understanding. More appropriate wording, from a communication goal perspective, would be "I understood the risks of my different treatment choices."

We were informed by patients' reports of their experiences with communication during cancer diagnosis and treatment in previous studies [5,11], and their responses to early drafts of some items [10]. We also reviewed a number of existing items sets (e.g., the Consumer Assessment of Healthcare Providers and Systems [CAHPS] family of surveys [12–15] including a newly developed cancer specific CAHPS survey [16], previously drafted unpublished items developed by two of the authors (KM, RS), and prior work on PCC item development funded by the National Cancer Institute [17,18].

Items and response options are provided in the online Supplement table (Appendix A). We created seven item sets for a total of 74 items: "core" items which focused on the time from the suspicion of cancer through the present (16 items); diagnosis (5 items); deciding about treatment (19 items); surgery (9 items); radiation treatment (10 items); chemotherapy (10 items) and after treatment was concluded (5 items). Items on surgery, radiation and chemotherapy were only administered to respondents who reported they had that treatment. Responses to these items ranged from *never* to *always*, or *strongly disagree* to *strongly agree*. Respondents could also choose *does not reply* as an option. Each item set was followed by a single item soliciting an overall rating of communication during the portion of cancer care referenced (response options ranged from *poor* to *excellent*). Respondents who provided an overall rating other than excellent were asked to describe where communication "fell short"; responses to the open-ended items will be reported separately.

Additional survey items included questions on cancer diagnosis and treatment, self-rated current health, and a single item on willingness to complete a questionnaire about communication experiences during cancer care. Limited demographic information on respondents was drawn from an existing database described below.

2.2. Sample

The survey sample was selected from a large healthcare system's existing online member research panel [19]. Panel members were randomly selected from the population of adult patients registered to use the provider's online patient portal. When patients join the research panel they complete a registration questionnaire and report their demographic characteristics. Once on the panel, patients participate in surveys and other research projects, and receive a small incentive for doing so.

2.3. Survey administration

A random sample of panelists was selected for this study. Respondents received an email survey that first asked about their cancer history. Only those who reported a cancer diagnosis, and were not employed by the health plan were asked to continue with survey. For the purpose of this study, respondents were not required to have received their cancer care through their current healthcare organization. An incentive valued at $10 was provided. Two reminder emails were sent to non-respondents, the first approximately one week after the initial invitation and the second approximately three weeks later. After approximately six weeks total the survey was closed, and no additional responses were accepted.

2.4. Analyses

2.4.1. Analysis of Does not apply responses

We examined the percentage of respondents choosing *Does Not Apply*. If a large percentage of respondents selected this response option, it would suggest that the focus of the item was not widely relevant. We also examined whether the percentages of patients choosing *Does Not Apply* differed for patients reporting non-melanoma skin cancer and those reporting other more serious cancers. We reasoned that some communication goals would be more important to patients with more serious cancers than to patients with non-melanoma skin cancer.

2.4.2. Correlations

We examined the relationship between individual items within an item set and the corresponding overall rating of communication using bivariate correlations and multiple correlations. Bivariate correlations were computed between an individual item referring to a specific aspect of communication within a care phase (e.g. "I was told I had cancer in a way that was sensitive and caring.") and the corresponding overall rating (e.g., "Overall, how would you rate your experiences with communication when you were diagnosed with cancer?"). Multiple correlations were between the full set of specific communication items for a given phase (e.g., for the five items focused on specific aspects of communication around diagnosis) and the overall rating of communication for that phase. We reasoned that if the individual items within an item set captured the most salient aspects of the patient's communication experiences during the corresponding phase of care, then the overall rating and the ratings on the specific communication items would be highly correlated, and the items within a set would

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